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Interviewee: **Betty Williams**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Interview of Betty Williams
August 23, 2008

SARAH SCHULMAN: So, we start if you tell me your name, your age, where we are, and today's date.

BETTY WILLIAMS: My name is Betty Williams. I turned seventy on November second of last year. We're in my apartment right now.

SS: What is today's date? That's a good question. I don't even know.

BW: August 23, 2008.

SS: Okay, great. Thank you. Where were you born, Betty?

BW: Right here in New York.

SS: Oh, you're a real New Yorker?

BW: Yes, a real one.

SS: Wow. Did you go to school in New York?

BW: I went to school in New York until I was ten, and then we moved to Connecticut, which is not a place that I ever want to live again.

SS: When you were growing up, did your parents have any kind of values about social justice or community responsibility?

BW: No, they were pretty much political dinosaurs. My mother had two things she taught me which were unusual for that time. One was that the internment of Japanese was very wrong, and, number two, that our treatment of Native Americans was very wrong, although they were called Indians then. But those were very aberrant.

SS: What do you think led her to realize those things?

BW: I really don't know. I mean, politics and social issues were discussed so seldom in my family, I have no idea.

SS: So what were their values? What was emphasized for you?

BW: Not very much. I really had to make up my own.

SS: Whenever you would become aware, as a family, and I'm talking about in your early years, whenever they would become aware of an injustice within their own realm, what was the attitude about intervention? I'm asking this because one of the many amazing things about your life as an activist is that you've often intervened for people who you are not, showing that type of responsibility. What was their attitude towards something like that?

BW: Towards my wanting to do things?

SS: No, when they saw other people in need around them, not abstractly, like Japanese being interned, but somebody in your community, for example.

BW: Well, basically, the people that formed our community were so privileged that not much bothered them except potential violations of the zoning laws or something, or, you know, a little bit of garlic getting in the salad dressing at the country club. It was just a sort of fear and paranoia, fear of the other.

SS: Had they also grown up in a privileged environment?

BW: Yes.

SS: So it was many generations?

BW: Yes.

SS: So when did you first realize that you wanted a different kind of life?

BW: When we moved to Connecticut, almost instantly. I guess the other very formative thing in my life happened before then, was on the day of Hiroshima, was the first historical event that I learned about on my own. My father was in the Air Force, but in England with his old boarding school and college chums, in a safe job. But I knew that after V-E Day, he would probably be going to the Pacific and potentially be in more danger. But all of these things I knew because of my mother telling me. But on that day I walked in the kitchen and the radio was on and I heard this and I instantly understood. I understood that this meant my father would come home and be safe, but I also realized that something so really evil had happened that it completely outweighed the issue of my father coming home, and, sadly, I also knew not to say anything, and I didn't until I heard on the radio that MacArthur was advocating dropping another bomb on China.

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I remember I went out to my parents and said, "This is wrong. When children my age grow up, we will see that there's no more war, because you've been scaring us to death all these years and saying, 'Oh, there was the First World War, we didn't things quite right. Now we're having the Second World War, that'll be the end.' Now there's another war, and plus, you're dropping these kind of bombs."

They immediately came up with this, "Oh, we just left out one other thing that we need to fix: the Russians, the communists," this and that.

I remember just standing there, I was ten years old and just thinking, "Remember how you feel right now. Never forget it, because grownups will always find a reason why there's war. Never forget how you feel right now." And in fact, my generation grew up to be the silent generation, but those few friends I have my age who shared my feelings, we all are pacifists and have been all our lives.

SS: So you had a personal revelation about pacifism. When did you first express that to other people?

BW: Except for that one try with my parents, who did not say, "There are other people who believe the way you do," or anything. If they did, they would have said, "They're pinkos and bad people, and stay away from them." I had no idea. Until Vietnam, I had no idea.

SS: Vietnam is a couple of decades later, so what happened to you in the interim? Where was your educational track?

BW: I went to school in Connecticut, then boarding school. I was very much sort of a lost person, I guess. I was sort of the mother in my family, of my own parents, who were not very competent, and of my brother and sister. I had nothing left for myself. I went to college because I was supposed to, because I was sort of manipulated into it because, "You have this kind of IQ and you can go to this college," and so forth, and sort of deliberately flunked myself out. Then I went to Parsons, graduated from there, and married soon after, worked as a designer, had my own modest little business for quite a while.

When my husband began to use drugs, got out of control, it was the end of my marriage. That's when I really began to grow up, was not really till then, in the mid-seventies. At that time I also became a Quaker, I guess partly in result to the election of Reagan. I thought, "It's just too much being a pacifist all alone. I have to find something else." I became a Quaker and was getting less and less satisfied with doing interior design. I liked working with architects, but I did not like working with clients because it's a serious issue, your nest, where you live, and all of these issues would be sort of

cloaked in superficiality and a certain amount of being very spoiled and whiney, and it was really hard to care a lot. But I really wanted to deal with how people lived in sort of more serious ways.

Suddenly a way opened. I had the opportunity to start a shelter for homeless people at Fifteenth Street Friends Meeting, with a friend of mine who also is an ACT UP member, John Maynard, and that really changed my life a lot.

SS: This was in the early eighties?

BW: Yes. Remember when that church-run so-called emergency shelter movement began in '80 or '81? It was basically a massive sepulcher-whiting effort on the part of the city. It was during the Koch administration. There were sort of some well-known, rather flamboyant homeless people, ladies in voluminous costumes sort of towing little chains of shopping carts and stuff. It was all over the news, after Reagan went out of the housing business, basically, and out of the mental hospital business, and out of the TB sanitarium business, and there was everyone on the street.

We started a little shelter. We were there every morning, every night. We had a small band of volunteers, some of them homeless friends that we had around the neighborhood. I'm happy to say it's still running to this day, except seven nights a week, 365 a year.

SS: How many people did you house?

BW: Depending on the configuration of the space we had and how many cots we could squeeze in, between twelve and fifteen. They were older adults, men and women with histories of mental illness and of program resistance. Suited us fine.

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SS: Did people come in off the street, or were they referred through Social Services?

BW: No, they were referred through, at that time it was from drop-in centers, at that time it was the one in the old Moravian church on 30th and Lex. The poor things, they never got more than six hours' sleep a night because HRA [Human Resources Administration] supplied transportation by buses and vans, the cots, the laundry, etc. We went into it just thinking we'll learn what we're going to learn from the people that we're serving, from our guests, and it became quite clear that this was not a winter emergency just caused by cold weather, that it was a chronic state in people's lives.

SS: I want to ask you about that period, because you had brought up the issue of the closing of certain kinds of institutions, and that's historically how people explain homelessness of that period, but at the time did you understand that gentrification was taking place, or was that something that was only understood later?

BW: I knew that the flops were either closing down or taken over by HRA. We went into it, John and I, very apolitically. In the beginning you're so overwhelmed by coming in such close contact with such human distress that you're not really thinking about gentrification or not. We knew the flops were not available because actually the involvement of Quakers at Fifteenth Street had begun many years ago in a way that seems so strange now. They had something called patrols and they would go out at night, and when they found people passed out on the street, they would wake them up and ask them if they would like to go to one of the flops and just take them there and

pay the five dollars or whatever for them to spend the night. If they wouldn't move, they had those kind of aluminum blankets they would put over them.

The flops were all being taken over and, of course, there was the business of closing of Columbia, tearing down all the SROs on the Upper West Side, which actually caused a lot of homelessness but made it possible for us, strangely, to continue to run the shelter. We used to run it for as long as we could every year and then just when we'd burn out, we'd have to close because we just couldn't cope anymore.

The end of the first year, I got a phone call from a social work student from Columbia who said, "I'm calling for Dr. something or other, who's a professor there, and he feels the people running shelters in churches and synagogues are doing the toughest job in the city with no help. Can you let me know what you would need to help?" And I just laughed hysterically into the phone for several minutes.

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00:15:00

They started a training program, which also spelled out just—I mean, everything about how homeless people were treated and the coverage they got in newspapers was like, "Oh, this brave social worker who sees her clients on the traffic islands in Broadway on the West Side." I mean, hello, you think this is great that folks have to live receiving help from people who have to crouch on traffic islands with them in the middle of Broadway? Is this just a good story? Are you looking at what this is really saying?

Then Ed Koch decided to give a thank-you party for people who had worked in and run shelters. Earlier that year, he had staged this ridiculous thing where he came downtown, and he's a tall guy anyway, and he came with all of his minions on this kind of public relations junket. There was a woman I remember that used to be around

St. Mark's Place and Astor Place, and drove up as far the Queens Midtown Tunnel, and she had this whole caravan of shopping carts and a big, elaborate outfit, but people like that are frightened, and he swooped down on her and said, "I want to help you. Would you go into a shelter?" She fled in terror, and he stood and did standup for the press and said, "See, these people are so crazy, you couldn't help them if you wanted to."

So when John and I got our invitation, we actually, our Quaker meeting, at our request, wrote a minute, which is a serious thing, and in our meeting for business, explaining that we would not be accepting the invitation because we felt that his behavior on that occasion did nothing but frighten vulnerable people and reinforce bad stereotypes against them, and lest his performance at that party inadvertently create that effect again, we could not go.

And we didn't go, and everyone else that we had gotten to know over the year did go. I never got so many phone calls in one week in my life, "How did you know not to go? How did you know not to go?" Apparently in the first place, he had served elaborate hors d'oeuvres and cocktails, and, of course, everyone who did shelter work at that point was so neurotic, we couldn't drink anything but instant coffee in a plastic foam cup with ten packs of sugar in it or whatever. There was a piano player, and then Koch came out and made horrible jokes about mentally ill homeless people. So I think that did a lot of politicizing.

Finally, some of us from the churches would get together. At one point, we wanted to tour the old men's shelter, the Third Street and [Bowery] . We finally actually managed to talk our way into there—they didn't want to let us in—because we

said, “We have people staying with us who spent part of their time with you, and so to help them effectively, we want to see what goes on.”

So we were ushered up to the top floor. I remember the director there at that point, there was a whole level of staff at HRA at that time who were old alcoholic guys, and their buddies didn’t want to fire them, so they’d give them these kind of jobs here and there. This guy, his office had, on top of all the filing cabinets were just these huge not even folded or neatly rolled-up pieces of paper, but long computer printout, just looped and piled up here and there, some of them with brown crackly edges, they’d been there for so long. There were so many cockroaches crawling around on the floor. I remember it was summer, some of us had on sandals. I was poking all my friends under the table and saying, “Lift your feet up off the floor. Put your bag on your chair.”

This guy, sweating bullets with a big red face, was just droning on about whatever it was he thought he was doing there. It smelled so horribly of urine in the whole place, I think they mixed the plaster with it. It was just horrifying. Seeing things like that was how we learned.

SS: I have a couple of questions to ask you. First, about doing it in a Quaker context, do you feel that your religious commitments were motivating you?

BW: Yes. Absolutely.

SS: And has that been true all the way through? Okay. How do Quakers work in coalition with other churches? Do you simply not discuss theology or—

BW: No, if it’s about—certainly with a shelter thing. Sometimes we would have meetings on our own, away from HRA and the Partnership. With the

Homeless and so forth. We would pray together or talk about ways to find the strength to continue the work. Sometimes if I was asked to facilitate a meeting, I would just say, “There’s one thing I’m going to do just because there’s so much kind of blah, blahs going on, is ask us all to sit in silence for a while.”

SS: I’m asking you this because the role of the Catholic Church in serving homeless PWAs has always been very controversial, especially in ACT UP. I’m wondering when you’re working in coalition with other religious organizations who have various kinds of discrimination beliefs, how you negotiate that.

BW: Generally our belief is that the real test of being a Quaker is that where you get along with people, you get along, where you disagree, you disagree, but you look for either deeper or higher ground on which you can meet, while still not abandoning your own principles. The Partnership for the Homeless was somewhat iffy in many ways. Their Cardinal Cook Award, that’s the other thing that we quickly learned not to go to. I went the first year and they were giving out this Terence Cardinal Cooke Award, and all these people that got the award were these horrible, crass real estate people. I just grabbed the friend I was with and said, “There’s too much sepulcher-whitening going on here. Let’s get out.”

SS: What is sepulcher-whitening?

BW: Sepulchre-whiting. In the Gospel of Matthew, they talk about whited sepulchers. It’s like a Potemkin village, whitewashing coffins.

SS: I see. In terms of yourself as a service provider, what do you do when people come in who have an incredible range of needs that you can’t provide?

BW: All we could provide – also, we ran the shelter with volunteers entirely, and I would stress to them, “The first thing you have to do every night is make sure that every person who comes in has a cot, blankets, sheets, a pillow, knows how to get a cup of coffee, has soap and a towel, and knows their way around. Only then can you address individual issues. Make sure that everyone is served.” Because there’s always someone who blasts through the door and attracts everyone’s attention, either because they’re more funny or more pathetic or more controlling or whatever, or they’re saying, “This is just an accident. I’m really not homeless. If someone would just help me get this job.”

I would say, “What can you do? Where could this person call you tomorrow? Could you just walk out of work to help them?” Because there are so many— it’s a year to undo the damage of one night on the street. It’s just such a radical step, and people would be all over the place. You have to really focus and think of serving everyone equally and respectfully.

Actually, you just learn not to be a rescuer. We gave ourselves a treat once in all the time that we did that work. One night someone called us from outside the building. We went out, and in the bushes around the meeting house we found this guy just reeking of alcohol, filthy dirty, and sort of raving away in Spanish. John speaks Spanish and got his story. He had come up from some, Peru or somewhere, via Ecuador. His family had chipped in all their silver and family ornaments and stuff for him to come up here and get a job and send money home. He had learned how to sew on a sewing machine, and he got up here and found that there were different kinds of sewing machines. He couldn’t get a job. He was in this SRO, and someone came in his room

and robbed all his stuff, including his little address book. He had relatives in Chicago. Of course, if you don't really speak the language or anything, you can't remember addresses or anything because they have no meaning to you, so he was just lost. He went into the park, into Stuyvesant Park, and someone offered him alcohol, and he just stayed in there and drank for about five days and then staggered out. He had figured out that we were a religious institution.

I remember John and I just kind of looked at each other, exchanged this look, and we said, "Shall we?" And we took him home and then I took his clothes back to my place. John cleaned him up in his place. I washed his clothes. Came back the next morning, we fed him, and he was actually completely sane. Breakfast and a cleanup had done wonders.

We had thought of taking him up and down Riverside Park, where people have soccer games on Sunday. We thought "No, let's just take him—." I think we took him on the F train out to Queens and we saw a whole bunch of people that looked just like him, we got off at that stop and asked for help, found someone from his country who had a connection at the consulate, and was going to help him. But, things are not done so easily in the world of people who are homeless, for varieties of reasons.

But the other thing that I learned from week one, the Moravians sent us their break-in crew, the people who teach you how to do stuff, because we had everything in these giant black Hefty bags that HRA had sent. We didn't know what was in the bags. We had to stuff them in an old coal tunnel under the street and drag out cots and put them between the tables in the cafeteria. It was like the Marx Brothers open a shelter, really. These kind, gentle folks came in and showed us how to do everything and

whatever and how people—they did not want their beds tightly tucked in; they wanted to choose how they wanted their sheets and so forth.

One of the men who came seemed in very poor health, and two days later, someone came and said, “Oh, they took him to the hospital.” He was in cardiac intensive care. So I went to visit him, along with a couple of his friends, and visited every day. They were really my teachers. His friends would take me on little tours here and there.

Do you know, in the old days, before they fixed up the ground floor of Bellevue, many homeless people lived there? It was completely self-regulated. They knew exactly how many people could be there and not attract attention and what level of behavior needed to be followed to stay there and not attract attention. Then if someone came that said there were too many people, or was not acting discreetly enough, they would get rid of them. They would take me around and show me all sorts of things like that.

Then Ted was given basically a death sentence at Bellevue, that his heart was not strong enough to withstand any kind of artery-replacing or valve-replacing surgery, because his heart itself was like an old wet paper bag. He was discharged back to the drop-in center, right from the CICU. So I used to go and sit with him every day up at the Moravia. At that time everybody smoked, so there were these choking clouds of smoke. I would bring him up low-sodium food and stuff. Part of the rules that govern drop-in centers is that you can't lie down. So here's this guy with edema and just out of the CICU.

Needless to say, he ended back in the hospital, and one of the doctors heard what had happened and wanted to put him in a rehab unit, where he could learn,

like, you have resting your arms on a table so you don't wear yourself out, sort of how he could do his daily activities without exhausting himself. He was supposed to be discharged on a certain day and go right into this rehab thing. Two days before that, I get a phone call from him, "They want me to leave today," and he was panicked. He said, "I want to go. These creepy people keep coming in. They tell me I have to leave or go to an adult home. There's all these rumors about adult homes and they really turn you into a slave," and so forth. They are pretty unsavory, in general, anyway.

Everybody that I knew, that I relied on for advice and help, was out of town, at a conference that day. Everybody. He was so timid and frightened that I didn't want to be out of phone contact with him for the time that it would take me to race up to Bellevue, because I just knew he'd be out the door. Finally, I managed to reach my main advisor from out of town and she said, "It's the Medicaid utilization review. They do sweeps, and this is the day. If you can keep him in today, they won't be doing sweeps again for two weeks." They were trying to boot him out, even though they knew he was scheduled to go into that rehab.

So I knew that I couldn't say, "It's just your fear of being abandoned and rejected that's making you want to leave. Just stay." I just said, "Ted, you have to promise me something. I'm coming up. Do not put your feet flat on the floor till you see me. Do not put your feet flat on the ground until I get there. Do not get out of your bed. I don't care if you have to pee, whatever. Wet your bed. Do not put your feet on the floor."

I also, with the person that I had reached for advice, she said, "Just keep him in until five o'clock and then you're safe."

I said, “Jennifer, if it comes down to it, do you think if I just lie on top of him and start praying, they’ll leave?”

She said, “That’ll clear the room.” So I knew that if I did that, we would be okay.

So I whipped up there and he stayed in. Fortunately, the person who then came and approached him about going into an adult home, he said, “Oh, I think she’s like you because she wears sweatpants.” So he went to the adult home, but then there he fell prey to his usual weaknesses, an interest in a young man and an interest in alcohol, and he ran away a couple of times. He would call me and I’d meet him at the Arby’s in Port Authority and cart him back out there. But eventually, he just disappeared.

SS: Is that how you first became aware of AIDS? Was it through the shelters or was it—

BW: No, I became aware of what it was like to be homeless and have a serious illness. Then my oldest and dearest friend from Parsons got sick the next year. He was diabetic, so at first we thought, oh, this is like when he gets diabetes. When he first got diabetes, he was on the classic sixties’ hitchhike-around-the-world thing, and of course he got every kind of pip in the world because he was actually getting diabetes. And we thought, “Oh, maybe his diabetes is getting worse. He’s getting all these weird things.” But it was back in the days when it was called “gay cancer.” It wasn’t even called—what was the next thing you were supposed to call it? GRID. That hadn’t even appeared yet.

I realized on that twentieth anniversary of HIV thing, that he was one of the first 1,115 people to die in this country. And I was there for one of the first 1,115

Tape I
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people who learned how to take care of a friend, because in those days, in the hospital—he was in Beth Israel, where a lot of people went, because it was considered to be an autoimmune disease, and so they were in the joint disease part of Beth Israel. He started spiking this series of fevers. It was on Labor Day, I remember just twenty years ago—next weekend it will be—and all of the interns and residents were rotating, so there was this whole new group of interns and residents, and they all were joking about how drunk they'd gotten the night before. They all went out and got drunk at that time, and came to work with horrible hangovers their first day of work. The first time I took a look at that little tradition, I thought, "These hungover idiots, these callow creatures, are here, responsible for my friend?" He had this horrible fever, and we had to go screaming up and down the hospital to get a refrigerated mattress under him, to get the order for that because these bozos were so callow and out of it.

For the next month, twice a day he spiked a fever that would have killed him if we hadn't gotten the mattress turned on, and then you take a basin of ice water, put towels in it and put it in his armpits and on his scrotum. Remember that, everyone, if you ever have someone who spikes a fever, that's the way to cool them down. It actually saved Clint Smith's life once, when he did that. Karen lived near him, and I got her to go over and do the ice-water trick.

SS: Who is Karen? Ramspacher?

BW: No.

SS: Timour?

BW: How can I forget her last name? Who fought so hard on insurance.

SS: [Karin] Timour.

BW: Timour, yes. But we did that for a month, and I must say, those interns and residents really shaped up fast too. Instead of coming and talking about how hungover they were, they talked about, “Oh, I volunteered to do this in Israel last year,” and this and that presented a better side of themselves.

But toward the end, some of the nurses came to us and said, “We were so scared, because we don’t see people that are sick this way. We have sort of mechanical problems. We’ve had to hoist people around when half their body is in casts and traction and stuff. We don’t ever see people that are sick, and it was so scary. Basically, we wouldn’t have done much for him if you all hadn’t been there.”

SS: How did you make the decision to become an AIDS activist in addition to your homeless work?

BW: After George [Lahey] died, I was so traumatized by that whole thing, I didn’t know anyone else that had been—

SS: George was your friend?

BW: Yes. And his was the first memorial service, the very first for AIDS held at Fifteenth Street Meeting. I was just so traumatized by that. I didn’t have anything to do with AIDS. I was the only person I know that never went to see *The Normal Heart*, nothing. I had one friend who had a little shop across the street who was one of those people who had the tables, GMHC, and I thought they were all kind of really crazy, but Jerry would wait for me at night when I would come home from the hospital. He’d always be waiting, put his arms around me and walk me to the door and said, “You’re doing a good thing.”

Then some people at my Quaker meeting came to me, and they were all sort of businessmen and stuff, and they said, “If you wanted to develop a residence for homeless people, you could do it here, because people think you’re not a flake.”

I never considered myself a person that anyone thought—a person capable of opening a residence, but that idea kind of stuck. Even way back then, I said it has to be for people with AIDS, because the only other people that I knew to talk to about this at all were some of my homeless friends from the neighborhood. They were the other people I knew who knew about AIDS, who knew to go and get whatever kind of blood test people were getting then, not for HIV, because they didn’t have one, but they would go to Bellevue and get their T-cells counted every once in a while, and they knew. I could talk to them and I started asking them, “Are you seeing people that are getting sick? How are they treated?”

Of course, the horror stories came, mainly concerning women who were injection-drug users, who would get blown off by hospitals, who had PCP pneumonia, and were told that they just had bronchitis, because even then a diagnosis of PCP meant they had to house them, they couldn’t discharge them, make them a Friday night special on the doorstep of some drop-in center.

I actually believe that AIDS kind of existed among this group of people first, because if you look back, there was something called junkie pneumonia, there was something called the dwindles that addicts got, and I think this was another early AIDS population way too helpless to ever do anything for themselves on their own behalf. And I just started saying, “If we do a residence—.”

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The quarterly meeting, the Quaker quarterly meeting, said, “Go ahead and try,” and made us an official committee.

I said, “It has to be for homeless people with AIDS.”

Well, everyone thought that I was insane, and plus really neurotic people wanted to be on that committee, who said they actually hated mentally ill people, this and that, and just wanted to find, oh, a family, a struggling mother and if we just got her pots and pans and clothes for her children, she’d be fine. I said, “If that was the problem with homeless people, every Kiwanis Club in the country could house them.

SS: We have to change tapes.

SS: So did you open a residence for people with AIDS?

BW: Yes, we did.

SS: What was it called?

BW: Friends House in Rosehill.

SS: What year did it start?

BW: It started—it took so long—1994 or ’95 we started, after many fits and starts. I said, “Y’all have to deal with your own mental health issues. Then we’ll get on to doing this,” and I stepped down from the committee.

Then they finally called me and said, “Okay, okay, okay, we’ll do it for AIDS,” and I came back.

At that time, my dearest, beloved soul mate and friend at the meeting was dying. That year is more or less of a blur.

SS: But you came to ACT UP much earlier than that?

BW: No. When was it?

SS: You didn't come to ACT UP till '94?

BW: Oh, no, way before that. No, no.

SS: How did you get to ACT UP?

BW: We were having struggles getting our residence going, of course. I had a friend who was then chair of the Community Board 6 Housing and Social Services Committee, and she said, "Come to this meeting. Will you come to this committee meeting of mine at Bellevue?" She said, "I don't know quite what's going on, but they're accusing HRA of hiding people with HIV in the shelter there, and that's not legal, and everyone's making a huge fuss, and HRA is coming," and this and that.

I said, "Sure, I'll go." And I walked in the room, and there was the usual bloated alcoholic HRA public relations guys, and Nancy Wackstein, who was a supposed good guy, working – I guess by this time we were into Dinkins. No, it must have still been Koch. I don't know. But she was considered to be like a good guy. Then there was this group of young men at the other end of the table, all wearing ACT UP t-shirts, shorts, giant Doc Martens boots, and acting very wild. It was Eric Sawyer, Keith Cylar, Charles King, Rich Jackman. In other words, the Housing Committee of ACT UP.

At one point, Eric stood up and pulled out from his wallet the same pink shelter monitor's card that I had from the Coalition for the Homeless, to be sort of Callahan Decree¹ enforcers in the shelters. He pulled it out and said, "Well, when I came here last night to visit and told the security guy that I was going to Five East," or something, "he said, 'Oh, that's the AIDS floor,'" and to show them all up as total liars.

¹ In August 1981, as a result of the case *Callahan v. Carey* No. 79-42582 (Sup. Ct. N.Y. County, Cot. 18, 1979), the City and State of New York agreed to provide shelter and board to all homeless men who met the need standard for welfare or who were homeless "by reason of physical, mental, or social dysfunction."

And I thought, “Wow. No wonder we’re having so much trouble getting our project going.” I said, “I think I need to go wherever these guys are from. I need to go there and learn what to do.”

SS: Can you just spell out exactly what the issue was? It was that the shelters were not supposed to have people with AIDS?

BW: If you had symptomatic HIV disease, you were supposed to be housed not in a congregate setting. However the threshold for housing eligibility for homeless people was higher than it was for a middle-class guy who’s sick and loses his job, and HRA stepped in and paid their rent and so forth, because the city, in its wisdom, determined that living in a shelter was the equivalent of having homecare assistance. That was the whole “Housing, not shelter. AIDS won’t wait. Let’s go out and get arrested tonight.”

SS: So it’s not that they were pretending that people with AIDS weren’t in the shelter; they were saying that that was adequate.

BW: They also were pretending they weren’t there, that they weren’t all gathered together on one floor, so they obviously knew they were there. It wasn’t just a scattered bunch of guys who didn’t want to disclose their status; they had a whole little wing of them in the Bellevue shelter.

SS: So then you started working with the ACT UP Housing Committee?

BW: I was at Eric’s house for the committee meeting the very next week.

SS: What was that like for you, coming into ACT UP?

BW: I guess, I had tried before. I had gone a couple of times because I knew I had Quaker friends there, John Bohne and John Maynard. It was scary, and no one I knew was there. I sort of retreated.

Then the other thing that motivated me was that one of my dearest friends was getting sick and getting very angry, and we both agreed that one way to get our friendship through that was to go to ACT UP together. So for that little constellation of reasons, I – and once I started going to Housing Committee, then I knew people.

SS: So what was your first action with ACT UP?

BW: My first action was before I really was part of it, was the second Stop the Church thing. I had been horrified by the first Stop the Church thing.

SS: What second Stop the Church?

BW: The second Stop the Church demonstration.

SS: How come I don't know about this? Do you know about it?

BW: I guess the first one sounded like good idea, but then when I heard about what happened with the communion wafer and stuff, I was really horrified that anyone would do that, because it's a church, and I just felt violating other people's religious beliefs is just out of bounds for me.

Then somehow — I can't even remember who it was, but some group of people that I liked started urging me to go to the second demonstration, I guess John among them, and I sat down with some Quaker friends of mine, really seeking some sort of clearness about whether to do it or not. I said, "I've been invited to go, and on one hand I think I should go, because these are good people and I believe what they believe,

and I do believe what the church is doing is wrong, but on the other hand, it's this and that."

All of my friends, instead of saying, "Oh yes, this is a dilemma. Let's pick our way through it," said, "Sounds like a great idea. Let's all go together."

So I thought, "Whoops. Trapped."

SS: Do you remember what that action was exactly?

BW: It was just picketing outside. The usual, on a nice fall Sunday outside St. Patrick's. I remember being very nervous and getting there very early and dressed very respectfully. I remember John was there and the two of us ended up marching around in a pen, all by ourselves.

Later, I can't remember if it was Channel 4 or Channel 7, covered it on the evening news, and I was sitting, looking at the news, and the camera showed the demonstration, and I thought, "Oh, that's a nice little gray coat that person has on. Who is that?" It was me and John.

I can't remember her name, it was a woman reporter, something like Celeste Ford or something, said, "All of these violent gays and lesbians are marching around out there." Apparently there were so many phone calls that she changed her tune for the later evening news, whatever.

Then the rest of my friends, my Quaker friends, came. We all marched around out there and my friend Marjorie Cornwell, I remember, she suddenly looked up at the cathedral and she said, "This is a steeple house if ever there was one." Because the founder of Quakerism, George Fox, used to march around like a real nutcase outside

churches and berate them and say, "These are steeple houses. Don't trust them," and so forth.

I guess it was my friend saying, "This is a steeple house if ever there was one," and I thought, well, here I am with all of my friends in the right place, doing the right thing.

Then I actually went to the Safe Sex Six trial. With Charles, and I can't remember who all the other people were, there were six people who refused to take a plea and insisted on going to trial.

SS: What was their crime?

BW: I have no idea what they were accused of, because everyone was lying so badly, it was horrifying. That was horrifying. I remember just leaving and running into St. Paul's Chapel in tears at lunchtime because the police were lying about who was really the arresting officer, those sort of pink-faced guys that were those sort of ushers/enforcers at St. Patrick's were all lying. And all that anyone had done was engage in forms of protest that had been traditional in the Catholic Church forever, prostrating yourself in the aisle and so forth. That's what they had done. I was just horrified.

SS: So on the second Stop the Church, there was civil disobedience inside the church?

BW: No, this was still left over from the first Stop the Church, I guess. It took a long time for them to bring them to trial. And then we'd all go and have lunch every day in Chinatown. People were really scared. "Oh, we're going to end up in the big house," and so forth. It was really scary. There was a real chance that they all could have been sent to Rikers [Island Jail]. And I discovered all the other people in ACT UP

who were there for religious reasons, because they were all in the courtroom. We all came every day and we all were in tears from time to time to see that a church could behave so really horribly. But I also understood that that church is what it is. It's not about people expressing their faith on a daily basis; it's about money, power, control, real estate, whatever. It has nothing to do with St. Anthony's right here, where I go to Mass frequently at midday with a group of people who are simply there to worship. It's completely different.

SS: What were some of the projects you worked on in ACT UP that remain your favorite or the ones you're most proud of?

BW: Oh, the best one was when we fooled the police. It was just a little tiny thing. HRA had done something dreadful again that was risking people's lives, about homelessness. There were two workers at HRA who were real bad eggs. So we were doing our usual, stenciling things on the sidewalk at night and then marching around and so forth. But we were also a decoy thing for a larger plan, which was that Dinkins at that time was having a meeting in a building that looked out on the south face of the Municipal Building. We had determined, in the ways that we all could in those days, that he was going to be in a conference room that faced that view. Unbeknownst even to most of the people marching around in front of HRA, the plan was that Charles and Keith and the usual suspects, dressed, to their extreme pleasure, in hardhats and boots and so forth, had gotten into the Municipal Building, which was scaffolded, and they went in as construction workers and just stomped about and got up onto a high floor, where someone else had stashed a giant, giant, enormous banner, that said "Dave

Dinkins, keep your word! Housing, not shelter, for people with AIDS!” and dropped that banner right during the middle of that meeting.

We were just marching around in front of HRA, and suddenly two of us said, “This demonstration is going so well.” And they had the vans with these stupid policewomen in trench coats and sneakers and fingernails and hairdos and so forth, storming around with their little communications center. We just said, “Let’s just go down to City Hall and continue this because it’s so much fun.” And everyone was grumbling. We were just saying, “Shut up. March.”

We get down there. The cops are chasing us on their scooters. Mainly they’re worried, of course, about the Brooklyn Bridge. They think we’re going to do something there. So we get down there. We stop across from the Brooklyn Bridge entrance, and the little motorcycles all are buzzing around and lining up across the bridge. Then this banner drops. Even the cops cracked up; they laughed. They said, “You got us. You fooled us this time.” They thought it was funny. They knew who did it because they all came bursting out in their hardhats, and we were all hugging them and screaming and yelling. I loved that.

SS: What were you able to win from the city?

BW: We stopped people with HIV in shelters. We have more housing now, thanks to starting Housing Works and so forth. We also had a huge effect on TB when that became an issue along with AIDS, because by that time and in those days, we had relationships, friendly relationships also with people in DAS [Division of AIDS Services] and HRA, in city agencies, and in the Department of Health, who would tip us off about things or let us know things that really needed fixing.

For instance, at St. Vincent's they were covering up an outbreak of multidrug-resistant TB. A doctor there, who should probably still remain nameless, came to us and said, "We need your help." That was when, in the days of, was it *QW*? Eric and I, we had such a good time, we wrote a whole series of stories, of cover stories in that magazine. We let it be known we were writing it and we called people at St. Vincent's for quotes and comments, and they wouldn't speak to us and so forth. But apparently, they were all waiting at the newsstand by St. Vincent's when that hit the press. They grabbed the copies, they ran back in St. Vincent's, and immediately issued a policy relevant to the situation, because staff were not testing themselves, were not get tested or they were self-testing and covering things up. They just had no proper infection-control things.

More importantly, at that point, Woody Myers had retired and we had Peggy Hamburg [as New York City Commissioner of Health]. She had a deputy commissioner of infectious diseases who was sympathetic to our cause, and she and he leaked to us this hideous document that she had been saddled with from the Woody Meyer days. It was a plan that the city and state Departments of Health had cooked up together, sitting in a high tower of that insurance company on Madison Square Park, the one with the little gold pyramid top, MetLife, they had sat up there, well, already including being part of this prestigious working group on all their résumés and CVs, were coming up with this plan to house homeless people undergoing long-term treatment for TB in basically lockups. They were going to open buildings of unused mental hospitals. Fortunately, their work had ground to a halt over one single issue, indicative of the mentality with which we dealt, which made it easier. They were fighting over who

Tape II
00:20:00

would pay for the incentives they would give people for taking their medicine, which were to be cans of soda, probably off-brand. They were fighting over who would pay pennies for cheap soda to give these guys. So we had some wiggle room and we turned our efforts to that.

Plus Ginny [Schubert] and I had a secret informer. I never knew the person's name, but he fed us a lot of stuff too. So I continued writing about that in *QW*, and I got a call one day from this reporter from the *Daily News*, a very nice guy, and he said, "I just love these. I just go and buy that magazine every week," and so forth. And, "This is so interesting. Where did you get this information?" I told him, and he said, "You mean, you just believe this person? You don't even know who he is?"

I said, "Well, look. This is why I believe, because there was this sort of missing piece to the whole puzzle, and this fits perfectly, and this is why I believe it."

So I told Walter Armstrong, who was my editor at *QW*, I said, "Walter, I told him exactly every single thing that I knew because he said he wanted to investigate it."

And Walter said, "Betty, you could be a little bit competitive."

I said, "Look. He knows how to do it. I don't."

SS: Let me ask you something. Through all this work that we've been discussing, you're constantly coming up against bureaucrats who are not paid very much, who don't have a lot of power, and who are constantly dehumanizing people who are in need. Did you get any insight into these kinds of people and why they seek out being in a position like that?

BW: From knowing not those particular people, but other people who take those kind of jobs, a lot of it is security. There's a pension, of course. These apply less these days, I guess. There's a pension. There are benefits. You just grit your teeth for twenty years. But in the AIDS world, a lot of the people who originally went into DAS really went for good motivations, and I think that's why we really succeeded with Guantánamo so well.

SS: Let's talk about Guantánamo. Can you give a little background into that?

BW: Yes. In 1991, and '92, there was a coup d'état of then-president Aristide in Haiti in '91, and dictatorship resumed under General Cédras. Eleven thousand Haitians fled in boats, were picked up by the Coast Guard and taken to Guantánamo. All of them, on their arrival there, without their knowledge or consent, were tested for HIV at the same time that they were given, I think, seven different immunizations at once. These were people who had never, many of them, been to a doctor in their lives. Anyone who protested was put in restraints to have their blood drawn.

About three hundred of them were found to be HIV-positive. They noticed everyone else was being sent to the U.S. so they could apply for asylum. Asylum can only be requested in this country. Refugees are people who get to a place that can offer refugee status. In their own country, asylees have to get to the country they feel will keep them safe and apply for asylum there. These folks were kept in complete limbo, the ones with HIV.

Tape II
00:25:00

The real HIV ban had not yet been passed, but they were all herded into little school buses one day and taken to a remote part of the base, exactly where Camp X-Ray and Camp Delta and so forth are now, exactly in the same place, which is up against the Cuban fence line, which is mined, the ocean on another side, and just a sort of arid wasteland on the other two sides, and you can't see any other human beings. They were ushered into the camp surrounded by big rolls of razor wire. They had these kind of mini-tanks there with little bulldozer things in the front, all lined up ready to push into them. The military had those big bulletproof plastic masks over their helmets, were carrying big batons and had police dogs. Then a doctor in full military drag got up, and because it was believed that Haitians culturally did not have the same needs for privacy that the rest of us do, they were told over a loudspeaker, in the immortal words of Tuskegee, that they had bad blood, and that George Bush's doctor was going to fix them up, not to worry. They thought they were just lost, that no one would ever know where they were.

I still don't quite know how the Center for Constitutional Rights found out they were there, but they did, and a lawsuit was initiated by students at the Lowenstein Human Rights Clinic at Yale. When the judge started freeing a few people under interim orders, suddenly the attorneys realized they didn't know what to do with them, and they came to ACT UP and asked for help for people who knew about housing. I thought, well, I know about housing. I can speak French. I should help with that.

SS: Who came from the CCR to ACT UP? Who were the attorneys?

BW: I think they got Esther Kaplan to talk for them, to make the request for them. I don't remember Michael Ratner actually coming. I think it was Esther and

Keith and Bro Broberg and I went to the first sort of emergency meeting with people from the Haitian community. Michael had been conducting a sort of grassroots campaign over the summer because he knew that that was the only way to win. The Supreme Court has never decided anything, anything, anything in favor of Haitians, ever, ever, ever. He knew it had to be decided in the Federal District Court and not appealed upwards from there, and that grassroots support would be needed. They had a real struggle, but there were some people there. A couple of people who were George Bush “Thousand Points of Light” people, one guy from New Jersey who took the first few people and they all ended up in shelters and he kept all their I-94s, and was just a general fink.

The next thing that happened was that the only child in the camp who was HIV-positive and her grandmother were released. I remember it was the very first cold day in December, it was December 11th, and the plane was actually approaching Newark, and this Thousand Points of Light in New Jersey flickered out and said they wouldn’t take them. They said, “Someone has to step up and take them or we’re going to take them back to Guantánamo.” And Housing Works stepped up when they got off that plane in little cotton dresses and flip-flops. I always think of Suzanne as my little shepherd who sort of led me on the path. As it turned out, her cousin became one of my foster children from Guantánamo.

They also were releasing pregnant women who were exactly seven and a half months pregnant. They only had a medevac flight once every two weeks and they had this trap, like if they couldn’t make that flight, they couldn’t make it at all because in another two weeks they’d be eight months pregnant, and too pregnant to fly. So there was only one flight that was ever available to them, and it was that flight and they would

call Bro Broberg and me at two o'clock on Friday afternoon and say, "The flight leaves on Sunday. Call us by the end of business day today and let us know if you have secure supervised AIDS housing."

So the first few times we pulled it off. Then came a day we just couldn't. Housing Works would not take another person. They'd had it. Everyone else was full up. I walked over there twice and fell on my knees before Charles and said, "Please."

They said, "No, no, no."

And Bro and I took a really deep breath and we lied. We lied to the Justice Department. We lied to the military and said, yes, we had housing. Bro was working for the Coalition for the Homeless, which had a hotel that was better than most and safer, where they put some homeless people in crisis, and we rented a room there. That was such a scary week. I remember just knowing that we were lying, first of all, and trying to assemble some warm clothes for people who were seven and a half months pregnant, who we'd never laid eyes on, etc. We got them in that hotel room, and some Haitian women that we had met in our various meetings would sleep over with them and babysit for them.

We'd run around every day and ask people for enough money to pay the hotel bill that night. It was very nerve-wracking. Then we would walk them through DAS. Our method was we'd get that horrible little form filled out, and doctors never do it right, so then we'd have a friend who would get them on line in DAS the minute it opened. Bro and I would be crouching just down the block, outside the door of the HIV Law Project, waiting for it to open. When it opened, we'd rush in with a ballpoint pen and Wite-Out and doctor-up the forms and rush off and meet them at DAS.

One day we were doing that, and of course, all the women had horrible colds because they'd just gotten here. They had to pee all the time because they were very pregnant, and there wasn't even a bathroom on that floor, on the floor where people with AIDS were. Plus, there was such hostility toward people with AIDS, like down on the floor where people went for emergency money, you had to just hustle people through because there'd been some things of attacking people and getting mad and saying, "No faggot with AIDS is going to get their money before I do," and stuff like that. So it was very dicey going there and sort of horrifying, showing people this kind of introduction to this country, with graffiti all over the walls, and sordid-looking bathrooms, two floors away, and menacing people lurking around, and having to stand back behind red lines on the floor, and all the cashiers giving out checks and money behind thick bulletproof glass, like a midnight bodega somewhere.

Halfway through the day, the supervisor called me into her office and asked what was going on and I told her. She said, "You mean the city hasn't set up a special policy for Guantánamo people? We always had one for the Cubans, the Marielitos."

Well, that's all I needed to hear. I called Tom Duane. I just ran to a phone and called Tom and said, "Guess what? Guess what?"

Within a day, he had arranged with HRA a meeting. It was like the dream meeting. Every single person that all of us had always wanted to get together in one room, that we would work and work to get meetings for, and one elusive part of the picture would slip away. It was hard. Bro had to jump our folks ahead of some of his folks in the coalition for privileges. It was hard, in a way, seeing this meeting happen for

Guantánamo people that we couldn't make happen for other people, the people we'd been working with for so long. But I feel the reason that worked was because we offered people a chance to be a good guy, a limited chance. So it was not going to open the floodgates to some huge new category of people all screaming for housing; it was a limited group of people. For once, they could be the good guys that, in their secret hearts, I think all of them wanted to be when they took those jobs.

SS: About how many Haitians would you say that ACT UP was able to help accommodate through that program?

BW: Well, it ended up not really being ACT UP, but Bro and me. We actually – it almost killed us, but we resettled a hundred people. We became what the INS calls a VOLAG, a voluntary agency.

We went down to Guantánamo and had a very scary time down there. Bro was great. He was not fearless, but he acted fearless. I was petrified the whole time. They were so scary down there. I had spent so much time standing in peace vigils, but I had devoted absolutely no thought to what it would be like to be on a military base in the clutches of really crazy military people. They were all these old Cold War colonels who'd come out of retirement to do this. They were all the Judge Advocate General, the JAG colonels. They were like lunatics. We went at a loaded time. It was the week that Waco was going on. The judges' decision about closing down the whole place was way overdue.

As we were getting in the cab to go to the airport, someone handed us a fax of a suicide threat signed by fifty people in the camp, so everything was very tense anyway. We got down there and the colonel took us into his office and they yell – they

don't ever speak in a normal tone of voice, they at you all the time, and he was saying, "Have you seen *A Few Good Men*?" It just had come out two weeks before. We were way too busy getting ready to go and so forth. We hadn't.

He said, "They're not going to shoot at you."

I looked at him and I thought, "You're the one wearing camouflage. I'm the one that's wearing white. Who's afraid of getting shot, here, you paranoid freak?"

Then suddenly, this little underling came rushing in and whispered in his ear, and he got very flustered and said, "I have to go. I have to go."

It turned out some more people had tried to kill themselves as we were sitting there. For some reason, they decided that we were inciting people to do this.

Later, when the colonel resumed his yelling at us, I was still so naïve, I said, "Colonel Kleff, why are you yelling at us like this? We're here to work with you and it's going to be really difficult to work with you if you keep yelling at us."

He said, "I don't want to work with you and I'm going to yell at you."

We asked him exactly what had happened that caused the emergency, and he said, "Oh, Georges Barance is just asking like a fool out there."

I sort of scraped myself together and said, "Well, Colonel Kleff, this isn't really explained to us precisely what this person did. Could you be clearer?"

He said, "Oh, he put lighter fluid all over himself and ran up holding his lighter in his hand up by the rocks by the fence line."

And Bro said, "Well, what was your immediate emergency plan and your more long-term plan?"

And he said, "Well, we were going to wait and see what he did."

I said, "You mean you were just going to wait till he flicked his Bic?"

Then he got really mad. That was a horrifying look into the heart of the federal government, because they tried to make it impossible for us to work. They were so scary. Every day we had to fax a request to do our work to them, and we didn't have a computer or a typewriter. We just had this fax machine. They wouldn't come near us and they wouldn't give us any transportation. So we'd have to fax this thing over and then they'd cause all this trouble.

So the first day we were there to work, finally, late in the day. We'd been able to meet with the camp president and we had very secretly made a plan with him that we would see the fifty suicide-threateners first. We couldn't let the military know because we did not have theater and area clearance to deal with people who were suicidal. We only had theater and area clearance to ask people where they would like to be resettled, Miami, Boston, or New York. This is when the judges' decision is way overdue, everything is tense, everyone was threatening suicide, and we're supposed to ask them where they're going to live.

So finally, a little group of people – we were never allowed in the camp, never, never, never, which actually helped us with the folks, because that's the way they treated Jesse Jackson. They decided that we must be seriously scary people, too, and they did not haze us or give us any trouble. Plus they were really desperate. They really wanted people to talk to. So they brought this little group of people, and we had an interpreter with us. She actually was a law student whose father was a distinguished newspaper editor and comes from a distinguished Haitian family, but she could only go

to Guantánamo as a humble interpreter. Since I could speak French, all three of us basically, with help from what the military called “the migrants,” we were able —

Tape III
00:00:00

SS: You were talking about the people in the military called them migrants.

SE: They brought the migrants in their little school bus to this – we met with them on the former air base there, which was a beautiful, beautiful place, but they put us in this ugly, dark, dirty building, with one filthy semi-functioning toilet. We found old boxes of sheets. It’s where, if you ever saw pictures of those tent camps they used to set up for all the floods of people that came there, was there. We found old boxes of sheets and we covered everything with white sheets and tried to make it look nicer. Plus, sadly, had to use those sheets to pad the hard metal folding chairs for people that were really emaciated, to lie down when they came.

But that day we had our first round of interviews with people. We met as a group and then we divided them up and we had five minutes with each person. Then we met as a group again, doing suicide prevention, which Bro was a crisis intervention worker at the Coalition for the Homeless, and I’d had my barefoot doctor and barefoot psychiatrist training from Columbia University Community Services from the shelter, so we pretty much knew what to do. Plus, Amnesty International psychologists kind of helped us, shored us up a bit on the phone.

Then as the sun was setting, and this is the tropics, so—wham!—it just goes down within five minutes at six o’clock every day, suddenly the bus came back and all the screaming colonels and this scary marine major. We thought they were keeping track of who was on the bus because you never saw so many walkie-talkies and

clipboards in your life, of course. So suddenly, they came in and darkness was falling and they had these huge rifles with them, and they pulled out these rifles and crouched their knees down, and Bro and I said, “What’s the matter?” They said, “There’s only thirteen migrants on the bus and we brought fourteen migrants. How many migrants did you see?”

Of course, we hadn’t counted them that way. We’d, in fact, done exactly what Captain [James] Yee later ended up in solitary for doing. We had to get to know several hundred people who we’d never met before and we made up our own forms and we were nervously rustling through them, trying to count how many forms we had. Of course, the more we tried, the more nervous we got. We really were convinced they were going to kill us if they couldn’t find the fourteenth person, really. There were no phones. We were totally isolated. That part of the base was totally deserted. They were just going to shoot us right here. We’re going to be dead. We were just petrified.

I was so nervous in that building with these horrible people, crouching around with these guns in their hands, that I stepped outside and all of the folks were in the bus laughing. They all knew that I spoke French at that point, and they started saying to me in French that actually the fourteenth person had never gotten on the bus for this reason or that, and those stupid military stuck together at the assholes like a bunch of dogs, *macoute macaque*² and so forth. I was like half laughing, half petrified that then those creatures would ask me what they were saying.

² In an email dated August 30, 2010, Betty Williams explained: In French, it’s Macoute, macaque (Macoute as in tontons macoutes, Duvalier’s thug paramilitary (macoute is a woven bag peasants wear over their shoulder, or the bogey man can put you in and take you away), tonton means uncle or old guy. Macaques are a type of monkey and in Haiti in French, is the word for monkey. So it’s name-calling, “Macoute! Macaque!” In Kreyol, it’s “Makout! Makak!” same meaning, said in a sharp, barking voice, it means trouble, people are really mad.

SS: Oh, my god.

BW: It was so scary. Well, finally, thank God, they got a grip and realized they only came with thirteen people, and left.

SS: What medications were people receiving at Guantánamo?

BW: AZT and Bactrim. What was really amazing was that coming from a completely different information set and so forth, they made the same choices that I would have made. They didn't take the AZT. They had no shelter from the sun. It was treeless where they were. They were living in these horrible Quonset huts that became like ovens during the day. At that time, the theory was that AZT and full sunlight just crashes your immune system. They took the Bactrim, thank God, because they were familiar with it from Haiti.

Tape III
00:05:00

They did horrible things, like they gave INH [isonicotinylhydrazine] to everyone who was in a Quonset hut with anyone who had had a positive PPD test [a tuberculosis skin test], which was just ridiculous. I had known about this because one of our first Bro and Betty Three, those pregnant ladies, had said that she took INH. You never saw social workers run out of a hotel room so fast in your life. They started freaking out. I said, "Let's all calm down." I asked her if she'd had *peau d'orange*, a reaction where she'd had a PPD test. She said, no, they just gave it just on general principles.

I questioned and I talked to the people at the State Department of Health. They said that's a terrible thing to do, first of all, because all TB drugs are harder on people of African descent, and especially on pregnant women, and that you just do not give INH for TB prophylaxis to people who don't need it because all it does is create

resistance, especially since, of course, they don't take it. They just take a few and then stop and there you are, nice resistant person.

So when I pointed this out to the military, they all started yelling at me and said, "Well, that's what you do if a family were in a house. You'd give everyone in a house—."

And I said, "Those huts are not houses, and the way you deal with that is give people medically appropriate housing," which made them exactly as mad as the city's court council lawyers would get when we'd use that phrase "medically appropriate housing," here in court cases. It'd make them so mad.

SS: Were you part of the decision of the Housing Committee to become a separate organization, to become Housing Works?

BW: Well, it wasn't the Housing Committee that became Housing Works. The Housing Committee continued to function as the Housing Committee; just Keith and Charles' energies were going into Housing Works. But the rest of us were involved with that, but also continued with the Housing Committee.

SS: But were you in ACT UP when Housing Works was created as a separate entity?

BW: Yes.

SS: Can you summarize what the reasons were for that to the extent that you understood them?

BW: It was just a lot easier and more effective way to start a nonprofit. Having gone through it then, myself, later, it's not a process that can just be on the floor every Monday night endlessly; because when you get your funding, there are certain

things that you have to get done by certain points or you lose your funding. You have to be able to function.

SS: Now, when ACT UP split and people look back on the demise of ACT UP and all this kind of thing, one of the ways it's characterized is that there were some people who were not interested in issues like housing, Haitians, immigration, and were primarily interested in medication. Was that your experience? Do you find that that is accurate or do you think it's more complex than that?

BW: It was my experience, certainly. As you probably know, some of us split off and formed City AIDS Actions because, in my case, I had always seen AIDS as a condition of poverty. That was my real experience of it initially, and working with Haitians, of course, only intensified that.

I remember when we had our TB working group and Ginny Shubert, Terry McGovern, and about three or four non-ACT UP people and Mike Isbell and I wrote a paper resulting from that leak of Department of Health to us about their plans. Peggy Hamburg did it so that a better plan could be developed, and we did it.

Michael, at that time, was working for Lambda [Legal] and was pressured by the most active treatment activists, who said, "We are sort of HIV-positive AIDS professionals working with and exposed to clients regularly, every day at GMHC, and we don't want them running around with TB. Ditch these women and their inconvenient interests in homeless people and people who are addicted and mentally ill and so forth, and prisoners." To his great credit, Michael did not do that. I know he's been accused of being very elitist, but he stuck with us, and Lambda was the organization that had the

money to edit and print everything and do all that kind of stuff that we could not really have scraped together to do. So, yes.

SS: What was the event that made you realize that you really needed to start City AIDS Action?

BW: Just that there was no one left that understood the workings of DAS. What we used to do in the Housing Committee was we, just the way people became drug buddies and one person would learn each drug well, one of us would learn DAS, one of us would learn the state system, etc. I was the only person who knew how DAS worked and had connections there that was left. Also, we wanted to do actions swiftly and quietly and be the stealth initiators of actions.

SS: Do you know what year that was?

BW: It was '96.

SS: So you stopped being an ACT UP member when you started City AIDS Action?

BW: Yes.

SS: How did that feel to you?

BW: It was kind of sad. We were a very small group in City AIDS Actions, and most of the other people had come to ACT UP for the reason that I did, in part. Most other people did because they had friends who were sick and dying and were looking for another focus. I think I was the only one who had direct experience of AIDS as an issue of poverty. I always had that motivation. I didn't have to sort of scrape it up out of somewhere. Drew Kramer did, in a way, from working with Tom Duane and seeing what they went through, what some of his constituents went through and stuff.

But I felt ACT UP was my life graduate school. I felt sad by the combination of ACT UP users as opposed to ACT UP members that were appearing, some of them rather dishonest and some of them a little scary. It was sad to see the life go out of it.

SS: I only have two more questions left. Is there anything huge that you feel that we haven't talked about?

BW: Yeah, I'd like to talk about the connection that I saw throughout the work that I did. It was kind of my Guantánamo experience that brought it all back to me, coalesced it. Just the two years before I became involved in that, I read all the Basil Davidson histories of Africa. He was an English Marxist historian. I think the books are out of print now, but they were the first books that I'd ever read about Africa that were not about Stanley, Livingstone and Vasco de Gama, were about Africans. There was something that struck me very much in one of the books, that until the oversea chattel slave trade began, relations between Europeans and Africans were mutually respectful, as reflected in letters that they wrote each other and so forth, and it was only when the oversea chattel slave trade began that it brutalized everyone. It quoted a passage, it talked about slaves sobbing as they were loaded on the boats, partly, quote, "because they feared they would be going someplace where they could no longer indulge their carnal animal appetites," and, secondly, because they saw they were sailboats, but they had big kettles and stuff on them for cooking, and they saw the steaming pots and thought they would be cooked and eaten.

And I thought, "There's something here." They were the losers. We wrote history our way, which was even when I was a teenager, cannibal and missionary cartoons were common in magazines, of people with bones through their noses and frizzy

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hair, dancing around pots with missionaries cooking in them. And I thought, we got to write the story, but that primal fear is the key to a lot of the difficulties of people's fears about AIDS and treatment and everything that goes with it.

Then I read *Bad Blood*, the book about Tuskegee, and there's a part in that about a plantation where the slaves came down with a typhoid dysentery. They called a doctor to come and stay and treat them all. He built a replication of the same kind of slave quarters far out in the forest where they would be isolated from others and quarantined, essentially. When asked why he didn't build more comfortable housing, he said, "Oh, they wouldn't thrive in anything better. This is what they're used to."

I saw a film about Albert Schweitzer, the *Grand Blanc de Lambaréné*, who, when asked why his patients who traveled to his clinic lived in huts with goats, he said, "Oh," again, "they wouldn't thrive."

I thought of the "housing, not shelter" lawsuit. I attended every day of that lawsuit, *Mixon vs. Grinker*, and every day the city's court counsel, who talked like Arnold Stang, would say, morning and afternoon session, [imitating Stang's accent], "Your Honor, you couldn't keep these people in an apartment if you gave it to them. It's impossible. You can't keep them in an apartment."

Then the first that I actually ever heard of Guantánamo from Guantánamo, I woke up one morning to the radio and there was a piece and they were asking the military doctors, and they were questioning whether that camp was an appropriate place to keep people with HIV, and they said, "Oh, yes, it's much better for them here. It's a clean, nice place," not like those demonized urban areas, Dade County, Miami, or New York. Then he was asked if people were given condoms and appropriate education about

transmission. He said, “Oh, yes, but they’re really not capable of understanding it, so I’m sure that they’re all in there infecting each other.” And it’s those two ideas, that people are out of control sexually by their very nature, and that if you gave them something good they couldn’t attach themselves to that or thrive there, that have distorted us through centuries, and they’re still alive today.

SS: So it’s the same paradigms.

BW: Practically the same statements, just change as the language changes. Nothing else changes.

JAMES WENTZY: I do have something. We had about four or five ACT UP demonstrations regarding Guantánamo.

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BW: Yes.

JW: That was running concurrent with the buildup of the trial. Could you say something to that point, and was that proportional?

BW: We did the big Statue of Liberty thing at Rockefeller Center, because that was when there was the first hunger strike at Guantánamo, and Jesse Jackson and Al Sharpton joined in up here as well as—let me give him props—Olden Polynice, the Haitian basketball player, and various other people, Mandel Robinson, and so forth. We were told that President Clinton’s comment on it was, “Well, let’s see if they let Al and Jesse starve themselves to death. I want to see if any white people care.” Well, that’s all we needed to hear.

GMHC and Equity Fights AIDS really, really helped us. They bankrolled it. They rented a huge Statue of Liberty and wrapped her up in orange netting, and we figured going down and demonstrating in front of Federal Plaza is really a lost cause; it’s

cold and windy and no one sees you at all. So since there was, at that time, a passport office in Rockefeller Center—it was a huge snowstorm—we all laid down in the snow with Jesse Jackson, Herbert Daughtry. All the usual suspects, Susan Sarandon, Jonathan Demme, and so forth, got carted off to jail, which was weird. Jesse Jackson goes to jail with his own security people around him.

SS: How many times were you arrested?

BW: Only once, to tell you the truth. First of all, I have such a really common name, Betty Williams, that I was really mortally afraid of being put through the system, because they would not want to wait for the computers for a physical description, because they never would unless you had like Ruth Messenger and Ronnie Eldridge there in the precinct harping at them. And I have a real horror of being locked up.

That was my one bust. I have facilitated many, though. I was in the background of the Chain of Fools at City Hall for Chris Hennelley, when we chained the doors of City Hall shut. Also, do you remember in the beginning, the first year of the Giuliani administration, it did no good actual changes, but it did cheer everyone up, we planned from November, so we did it in April or May, very secretly, everyone met in noisy restaurants and so forth, only a few people knew, and no one knew the whole picture except about two or three people. I did legal support a lot in those days, before cell phones. That meant you were just glued, isolated, locked up in your house with your phone for forty-eight hours till you made sure everyone was out. At that time I took my kids and a little TV set and we went up to the workspace to do the legal support. I knew what City AIDS Actions was going to do, which was close the Queens Midtown Tunnel for the very first time, which is really scary technically. We had to plan a whole other

demonstration, something to do with insurance, because there was an insurance company near there, and then go marching up and then divert this group of people just enough to race across. You have to have enough people so the traffic will stop, because if you do it without enough people, they'll just run you over. Someone went into labor in the Queens Midtown Tunnel. We did let them out.

So I was there and I knew that other stuff was going on, and suddenly I saw, okay, the Brooklyn Bridge, okay, the Brooklyn Battery Tunnel, this and that, and every involvement, every single incident was a Guantánamo person. Lisa Daugaard, Bro Broberg, this and that, me, all the Guantánamo people running those. We had every Chopper 5 and Chopper 2 and whatever circling around. It was great. It didn't change a single thing about the budget, but it did cheer us all up, which we needed.

SS: I only have two last questions. The first one is a little vague. But most of the people in ACT UP were either people with AIDS or gay people, people who had been incarcerated. There were significant amount of straight people in ACT UP, but actually it was small compared to the world. You, like many of those people in ACT UP, had a long history of advocating for people who were not like you. What is it that made you be able to stand up for people who needed your intervention when the vast majority of people like you were unable to do that?

BW: I never saw it that way.

SS: That's what everybody says.

BW: I remember it was very hard because—oh, down the street, Bill, the lawyer —

SS: Dobbs.

BW: Bill Dobbs. When Chris Hannelley was beaten up, Bill was in his thing of not speaking to straight people. It was very humiliating and very difficult. But I just hung in, and finally he came up to me on the street and said, "I've decided that you're queer-identified, so you're all right."

I turned sixty when I was in City AIDS Actions. I used to be really self-conscious sometimes. When I first started writing for *QW*, they called me and asked me — I thought, do they know that I'm old, HIV-negative, straight, and a breeder with children in the house? I used to just run over there and slip my articles under the door and run away.

Then for my sixtieth birthday, people in City AIDS Action said, "Oh, we want to take you out for dinner." I thought, well, that's nice, because they had done something for Barbara Hughes when she turned fifty, and so forth. I didn't know the restaurant. They told me to come, and it was a really nice restaurant on the Lower East Side that was new, and the manager came out and said, "Oh, I'm really looking forward to this. It's just wonderful that you're here." Everyone just made a huge fuss. It was a lovely dinner and presents and this and that, and I felt like here I was, this sort of alien person if you just looked at our demographics. The committee met mainly at my house, because by that time I had James and Watson and Hill living with me, and so that I could be with them and see that the homework got done and so forth. We met at my house.

When the time came for making toasts and getting sentimental and so forth, everyone said, "You're our hero because we all want to settle down and have children, and you've shown us that it's doable. You led the way," and I really felt like that just summed up everything.

I would just think it's creepy to think, oh, I'm going to run around and find some way to identify with this person that's different from me.

SS: Right, I understand that side of it, but the other side is that most straight people didn't do anything during the height of the AIDS crisis. For the most part, people with AIDS and gay people were abandoned by their families, by the rest of the culture, to fight that fight alone, except for a handful of people like yourself.

BW: Well, if you'd watched your best school friend die, abandoned by his family, with nurses too scared to take care of him, and not scared of infection because we didn't even know at that point. We knew it had something to do with sex. We had no idea it had anything to do with blood.

I had a friend who was an artist, but also her day job was being a cytologist in the lab at New York Hospital. I remember one time she saw me trudging down the street and said, "Where are you going?"

I said, "I'm going to visit George. He's sick again."

She started screaming at me in the middle of the street, she said, "I've seen those cells. Don't you understand? You're going to die."

Then I have a congenital immune deficiency to a certain type of fungus and I got that infection from George when he was sick, and everyone was running around saying, "Oh, she's going to die. She has AIDS. She got AIDS from him," and all.

But we were so close and we looked so much alike. In those days, also, you weren't supposed to get to visit people unless you were in their family. No one ever questioned me because we looked so much alike. It was pretty scary to see someone—

we were in our mid forties—this beautiful, handsome young man just end up looking like Gandhi. I would just leave his hospital sometimes—it's so frivolous, I hate to admit it—I would have to go in some ladies' room somewhere and wash my face and put my makeup back on, just like put myself back together in some way, to face the world and convince myself that I wasn't going to just crumble away too.

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SS: I'm down to my final question. So, looking back, what would you say was ACT UP's greatest achievement and what do you feel was its biggest disappointment?

BW: I think its greatest achievement was to take on the federal government and force it to change the way it did some very major things. I think, to me, the saddest part was that some of the people who were so brilliant in doing that brought so much intelligence, devotion, but just to each other could not extend it. It's like the mystic, religious mystic, François Fénelon said, "Allow the mission of suffering to be fully accomplished in you." I feel that for many people in ACT UP could not allow the mission of suffering to be fully accomplished, and found it therefore difficult to extend their cause to people they saw as different.

SS: Thank you, Betty. Thank you for a fantastic interview. It's really wonderful. Thank you.