

Lolita: Okay, we're going, and if you can state your full name?

Shirlene: Oh, Shirlene Cooper.

Lolita: Okay. My first question, what has been the impact of HIV/AIDS in your life?

Shirlene: The impact of HIV/AIDS in my life is the overall trying to put an end to this epidemic. I've been diagnosed with HIV/AIDS in 1996, and I had a near death experience because of several opportunistic infections such as tuberculosis, cervical cancer, and syphilis.

Lolita: Wow.

Shirlene: And I spent eight months in the hospital being treated for tuberculosis. I was multi-drug resistance. So the medication wasn't working. And finally the hospital sent me home, and I thought I was going home to die. Eventually, I ended up going to another hospital in another borough where a different set of doctors decided they were gonna try to treat one of the diseases, and they asked me what was my choice. Because the medications for all these different diseases would interact, and you can't take 'em all together. So we're gonna allow you to choose which disease you want us to treat first.

So I wanted them to treat the tuberculosis because the New York City Department of Health wanted to quarantine me if I didn't get the treatment for it so I said, "I wanna go home. I don't want to be isolated in any rooms or away from my family and friends. So please treat that one," and they immediately did everything that can. It took two years of medical treatment in order for me to get over the tuberculosis because it was a rare stage. Trust me, I have no idea where I got a rare stage from.

Lolita: Okay.

Shirlene: I nearly died from it so after that, it was to go after the HIV and AIDS. I started a cocktail, which is HAART therapy, highly active antiretroviral therapy, and moving very slowly because the cervical cancer.

Lolita: Oh my gosh. Wow.

Shirlene: So they told me, "Well listen, we need you to get a hysterectomy, and after you get a hysterectomy, then you should start another regiment, another cocktail. So I went in, and I had the hysterectomy. Came home later for a few weeks. Then I started another regiment. Which is the second cocktail that I started on. And by that time I had over a million copies of HIV/AIDS in my system.

Lolita: You said copies?

Shirlene: Over a million copies which is ... a million copies of a virus in your body. And I had zero T-cells. So you're near death.

Lolita: Yeah.

Shirlene: They started me on a regiment, and the regiment was working very slowly. It took just like over a month for even to get like up to five T-cells, and it was scary, and I didn't understand the science or the math or what was next because I really didn't understand the disease, and I didn't know where this disease came from. I never heard of it when I was a child or even a teenager. So in my early 20s, I heard of this disease, and it was called a monster and I saw people in wheelchairs and turning gray and getting frail and thin, and they were just dying out of nowhere, and nobody knew what it was.

And then I come to find out I had it after the death of my son. My two year old son passed away from HIV and AIDS. I didn't know how he got it. But I was like ... well I must have it. So then I finally got tested. I was positive. And at that time, there was no medications to help save myself. So now I went on to try to save me. And try to put an end to this epidemic.

So I became a peer educator which was after the two years on treatment for tuberculosis, the year in bed trying to get up from HIV and AIDS, and I had got shingles, and that almost killed me in the whole nine yards.

Lolita: Wow.

Shirlene: After that, I decided I would become a peer educator. I was seeing a physical therapist because they was trying to sooth my pain by having me see someone and talk to someone, and she was great. She talked to me about my disease and what my life would be like and talked to me about my son. Just different things I wanted to speak to her about. And she came to me one day, and she said, "You would make a perfect person to share your story with to educate other women with HIV and AIDS that had gone through some things similar to what you've gone through. Would you like the job?"

And I was like, "Who me?" And I haven't worked in years, and I came from being very sick. But I immediately took the job because I thought it was something different, and it would worth my effort to start working in this field where I can help others like myself, and we all could come together and bond, and sort of kind of figure out a way how to bring an end to this epidemic.

So I was a peer educator for six months at Woodhull Hospital.

Lolita: Oh.

Shirlene: And their funds ran out, and that ended that chapter. But I met a guy who had started a not-for-profit organization called the New York City AIDS Housing Network, and we were just chatting, and I told him I said, "Yeah, you know, I just had a job, and they ran out of funds so I don't know what I'm gonna do next," and he said, "Well I have this organization," that they had just started, and they needed someone to come out and recruit other people living with HIV and AIDS. So that's it.

Lolita: Would this be part of the transformative?

Shirlene: [inaudible 00:06:22].

Lolita: Would that come under that maybe?

Shirlene: Yeah, yeah okay.

Lolita: Okay. I'm gonna ... Okay so let me ask you that just to make it official, let me ask 'cause that's a different, that's a good story.

Shirlene: Right.

Lolita: So yeah, I was gonna ask. Has HIV/AIDS been a transformative force in your life, and if so how? So that sounds like it's the beginning of it.

Shirlene: After meeting a gentleman who was also positive, and he had started a not-for-profit organization called the New York City AIDS Housing Network. He asked me would I recruit other people living with HIV and AIDS. So I said sure, I can do that, and it was \$10 an hour at the time. It was I just came from one job to no job, and I wanted a job.

Lolita: Right.

Shirlene: I wanted to be productive. I wanted to be independent as a person living with HIV and AIDS. So I took the job, and first thing I said to myself, "Well where are people with AIDS with?" Where would you find these people to recruit? In the hospitals where all the HIV clinics are. In the projects where the demographics are low income people of color.

So I took the flyers and the brochures out to all the five boroughs, all the projects in New York City, and to all the HIV clinics in New York City, and I recruited over 3,000 members.

Lolita: Wow.

Shirlene: And of course I impressed somebody.

Lolita: Yes.

Shirlene: They said, "You're a natural at this," and they said, "Well, we would like to give you a promotion to become an outreach worker and community organizer." So I said sure, you know, fine. I'll do that, and then the pay went up to \$12 so I was happy about that.

And I said, "I know what an outreach worker consists of, but what does a community organizer consist of?" So they put me in this training that was underneath their program called Power Academy. It was people organizing welfare and equal rights.

Lolita: Got it.

Shirlene: And went through the training, got my award. My certificate as well as award for being one of the top students in the Power Academy. And I became a community organizer.

Lolita: Wow.

Shirlene: So they told me, "Well we need you to go around on some personal days and see the type of housing they give people living with HIV and AIDS," and at the time in New York City, it was New Yorkers and landlords was renting bad apartments to people, inappropriate type of housing, to people living with AIDS, and the city was paying for it.

Lolita: Oh, okay.

Shirlene: So I started four tenants associations in four different buildings that were highly corrupt, and we managed to catch the landlords out there and let them know that they [inaudible 00:09:11], or move the clients out of the buildings because it was rat, roach infested. Some didn't have ceilings, door, sinks. But they was just renting to them, they didn't care.

Lolita: That's unhealthy.

Shirlene: The city was paying for it. We'll just throw these black, sick people in there. We don't care.

The four tenants associations led me to becoming the first African American woman to sit on the city council's HIV/AIDS service administrations advisory board. I was approached by city council speaker Gifford Miller in 2004, and I currently hold that seat on the Gifford Miller, three turns with Michael Bloomberg, and now with Bill de Blasio.

I'm also a HASA client. I receive benefits from the city's HIV/AIDS service administration. They pay [1599 00:09:59] for a one bedroom apartment if you have an AIDS or HIV diagnosis. We give the maximum amount of food stamps which is the SNAP program. And we get unlimited Medicaid because we see doctors more often than people who do not have HIV/AIDS.

Lolita: Wow.

Shirlene: In addition to that, after running the four tenants' associations, I was promoted to lead organizer. So I launched HASA For All which is the expansion. At the time, they were only giving benefits to people who had AIDS, not HIV and asystematic. So we were saying ... Well eventually these people are gonna transform into AIDS so why don't you just give it to them earlier, not wait, not make them have to wait. So that was HASA For All that the HIV/AIDS service administration would not only give to people with AIDS, they would give to people who were HIV positive.

And then I launched the 30% rent cap because people with AIDS had to go to social security and apply for disability benefits or just social security income. They was taking like 70% of your social security would go to your rent, and you have nothing left. So you would have \$11 a day which was impossible to live off of, a person living with HIV and AIDS.

So those were the two campaigns I launched, and then from there I became deputy director then co-executive director of the New York City AIDS Housing Network, and

currently I've gone to 46 of the United States and 35 countries organizing for people living with HIV and AIDS.

Lolita: Wow.

Shirlene: And to bring an end to this epidemic. Yes.

Lolita: Wow. Wow.

Shirlene: Yeah. So now today, I became an artist member of Visual AIDS. LOVE POSITIVE WOMEN is a project that was created by Jessica Whitbread. She started this LOVE POSITIVE WOMEN project so that women living with HIV/AIDS can make Valentine's Day cards out of paper, out of the Brooklyn Navy Yard, and send them around the world to other women living with HIV/AIDS in Puerto Rico, Jamaica, Uzbekistan, South Africa, and multiple countries.

It was amazing. It just opened me up. I lit up because I love art. I've always loved art, and they said, "If you become our artist member, we'll give you a grant," and it's a material grant where you can use independently or do whatever you would like with it. So I always wanted to start a woman empowerment art therapy group. That's what I did with the grant.

Today, finally, the group has just gotten funded. Yeah, the group has just gotten funded. We're gonna be operating under Visual AIDS, and we got funded by Naomi Taylor, Elizabeth Taylor's granddaughter.

Lolita: Excellent. Wow. That's ... Okay, let me turn this off. Thank you.

Lolita: If you can just a little more in terms of where you're going with this, where you want it to take you and your connections around the world, and in terms of just how you plan to execute your project.

Shirlene: As a community organizer and a person who's been organizing in 46 states and 35 countries, meeting with people around the world, around the globe, discussing HIV and AIDS and bringing an end to this epidemic, which the plan is to bring an end to the epidemic in 2030, so far, New York has had no babies born with HIV.

Lolita: Wow.

Shirlene: We're looking to bring it in 2030 because there will be no newly diagnosed cases, so it will just be everybody else that has it until that generation has gone, but there will be no newly diagnosed cases. That's how we're looking at an end to it. Then **this women empowerment group, this is going to help** women pass it down generation to generation and **keep women ahead of the disease instead of behind the disease. Just like myself, I prefer to stay ahead of it. As a peer educator, as a community organizer, or even as a facilitator or a**

host of the women empowerment group, I want to be in the front lines.

I want to know where this disease is going. I want to know when it's going to come to an end. If I'm not out there pushing myself and pushing other women and encouraging and enlightening people, that's not gonna happen, so taking that group, local, regional, national, and then international around the globe is one of my dreams.

Lolita: Okay. My question for my project is, what's the best thing that happened to you lately?

Shirlene: Lately, I became an artist member of visual aids and I received a material grant and I utilized my grant to start a women empowerment group in my very own living room. Since then, I have done the groups at Camba, Harlem United ...

Lolita: Can you tell us what Camba is?

Shirlene: Camba a non-profit organization that supports housing people living with HIV and AIDS. Harlem United is another not for profit organization that is also a provider, that supports housing people living with HIV and AIDS. We've had it also at Iris House, which is another non for profit organization for people living with HIV and AIDS, which does housing and supportive services and HIV/AIDS testing.

So, we've had the groups at these different organizations and we got quite popular. So, visual aids executive director Ester McGowan, decided that this was an amazing project. She wanted this project [inaudible 00:01:24] visual aids, and that she was going to put in a grant with the Elizabeth Taylor Foundation for a women empowerment art therapy group.

We got the grant. So, I'm very happy and I'm very excited about that. Her birthday is February 27th, so her granddaughter is flying in to New York City to meet with me, to give me the check in person, which is such an amazing ... Just amazing. So it just really got me excited and really got me happy. I'm looking forward to meeting with her. I remember Elizabeth Taylor having a supported rock concert for HIV and AIDS. So ...

Lolita: Yeah.

Shirlene: Me being a long term survivor and 22 year person living with HIV and AIDS, I'm very excited to meet her and to know that she's following up with her grandmother's work. She's trying to assist and help people with HIV and AIDS such as myself.

Lolita: Excellent. And what are your ... What ... In the future, what are you looking at in terms of the future? In terms of what you're going to do with this check, with this grant? What, where do you see yourself in just a few months in terms of all you're doing right now?

Shirlene: In a few months, I see myself of course as the manager, supervisor of this group and this group rotating around, throughout the five boroughs and possibly taking this group as I've done in my past, local, regional, national and then international.

Lolita: Okay. Excellent, excellent. Thank you so, so much, Shirlene. Thank you.

Shirlene: Thank you. Thank you.

Lolita: This has been great.