

## Priscilla Nkwenti

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**INTERVIEWER:** I was born in Cameroon, in West Africa as I could describe it. In some of the literature you come across, it's described as a central African country, so Central Africa, West Africa - but it's Cameroon where I was born. And I spent the first twenty or so years of my life there. I had a very very happy childhood, it was very loving, very calm, very beautiful, loving parents, you know, I have a house full of siblings. My dad is retired now, both my parents are still alive, and my dad was a civil servant, and he moved from region to region because of the nature of his job. So I think I went to about ten different primary schools before I ended up in boarding school. I went to an all-girls boarding school run by Irish nuns, in one of English-speaking regions – I come from the English speaking part of Cameroon. And I spent five years there, where I was grounded in all sorts of things, not just religious, but to be responsible, to grow up, you know, and to be responsible for your life, to look after other people. And I suppose to be leaders in community, in society, to look after your community.

And after five years I went to another boarding school, where I did my A Levels. Then I went to university. Unfortunately for me, the university I went to was more or less French-speaking in every sense of the word. I had grown up in the English-speaking part of Cameroon. The university, you know, there was only one main university in Cameroon at the time, and all my lectures – I did sciences for A Levels – all my lectures were in French, and I struggled, a lot. So I dropped out I think after the first term. I didn't last that long. And of course I discovered alcohol and boys and cigarettes; that didn't help as well. So I dropped out of university. My parents, particularly my dad being who he was, someone who believed very much in education, wanted me to get the best education I could, and decided that I had to go somewhere to carry on studying. So he sent me to England to come and study. So I came to England in the early 80s; I studied in Liverpool for three years, where I did my first degree, and then I went down to London to do an MPhil Masters by research. I met my husband whilst I was in London, and we got married, and I moved to Manchester to join him. That was in 1988. And I've been here since then.

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**INTERVIEWER:** OK. Great, thank you. What was it... how did you find it, moving from Cameroon to Liverpool?

**PARTICIPANT:** It was a big cultural shift, on so many different levels. In Cameroon, where I spent the first key years of my life, you're part of a community, you're part of a family, it's loud, it's noisy, you come and you go, you know. It's everything but England, you know, the weather is different, the food is different. I came to Liverpool because my family who had come to study in England were based in Liverpool. My Auntie Vera who I came to stay with, she had gone travelling. So one of my friends, he's of late now, picked me up and took me to her house. And the cold was just unbelievable. I came off the aircraft [in] Gatwick Airport, and I had to get on the train to get to Victoria, and then to get a coach from there I think to travel to Liverpool. And the England that I'd seen on postcards wasn't the England that I was seeing at

all, it was so different. I'd painted a picture of England in my head; it wasn't the England from the postcards I'd been sent, you know, [how] it was depicted to me. But anyway. I arrived in Liverpool, went into my auntie's home, and my friend, Sam, who collected me from the coach station, he, you know... I'd never seen a gas fire before. So he turned that on. And I'm sitting there. You know, the front of me is warm, my back is cold, and I'm thinking, where the hell have I arrived? And you know, he'd brought some food, chips and can't remember the detail of it, tasted it and I thought, I'm not used to this.

The first couple of weeks - I was skinny at the time, I didn't look anything like this - I didn't eat, because nothing tasted like the food I was used to. The food was very different. I found the cold really difficult to come to terms with. I had to go register at uni, you know, to go to lectures; I couldn't understand the Liverpoolian accent, the scouse accent, but I knew, if your parents are paying so many thousand pounds for you to come and study abroad, that you had to make the most of it.

My auntie came back after a couple of weeks being away, which was great, because some of my friends would come from different countries as well didn't have any family here, so it must have been a lot more difficult for them. At least I had family, I had friends. I had my friend Janet who was studying in the same university, so at least I had someone I could talk to, someone I could go to the coffee room and have a chat with. But it was... the first year, I was really depressed. And my dad used to ring me, and I'd just cry, because I just thought, I want to go back home. And he said, you've got to study, you've got to study. So he stopped ringing me after a while. And I settled. And I just thought, OK - after the first year, I got used to it, and I thought, OK, it could be worse, but I'm here now, so get on with it.

So I started partying again. I was going off to London for parties, I had other friends who'd come to study as well, and it was OK, it wasn't too bad.

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**INTERVIEWER:** And what did you study?

**PARTICIPANT:** I did Library Sciences for a first degree. That's what I did. And why did I- I did science A Levels, but I was looking at something I could study to go back to my country to apply. And at the time I left Cameroon, they were looking at, you know, the information science, not anything like what we've got today - they were looking at how to manage information within a bilingual context. And I started off with looking at, how do we curate information? How do we collect it, and you know, make it accessible to people who need information?

I grew up in a family where, one of the things my father got me to do a lot of, and I loved, was reading, and looking for information. At the beginning of the school year I would have read all the books that we had to read during the term. My dad would buy them for me. So in terms of making information accessible to people, it came easy to me, and you know, the reason why I wanted to do library science, you know, and at the back of my head, it was like, I love reading books, I want to make information, at the time we had libraries, we made information available and accessible to people - that was my passion. How do we make- whether it's literature,

books, or the science books or whatever, so people who wanted to get knowledge, to find the knowledge, could access, you know, whatever was accessible.

We struggled when- I went to university back home, and I dropped out, which really didn't have enough of the books that we should have had. You know, there wasn't enough information, not like today where you can go on the Internet and find everything and anything. Then, if you didn't have the printed copies, it was difficult. So we handed books around and everything. And I found that really challenging as well. Because if there were books that had been translated into English, maybe I wouldn't have dropped out. Good excuse for me. But you know, the teachers were teaching me in French, the textbooks and everything were in French, and I found it really difficult, really really inaccessible to me.

[00:09:19]

**INTERVIEWER:** [Mike asks interviewee to adjust her mic and the interview setup.]  
[Break]

[00:10:13]

**INTERVIEWER:** OK, so you did Library Sciences. How did you first - and then you went to London to do your MPhil - how did you first, when did you first start thinking about working in the health sector? How did that come about? Was that much later, or-?

**PARTICIPANT:** Much much later. When I was studying in Liverpool as an overseas student with limited resources, I did get a government-sponsored scholarship the second year of my studies, which wasn't too bad, so at least I got some support. But it's usually so difficult, you know, so the kind of jobs you look for, you look for anything. You know, I'd wash plates in a restaurant, I was an usher in a cinema, I did all sorts. I did playschool during the summer holidays. When I went to London, I did admin stuff on a part time basis whilst I was studying. I wasn't thinking about a career in health.

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**PARTICIPANT:** I'd moved from accessibility of information, to how we manage information in a bilingual system, where things can be a bit tricky. That's what I did in my Masters in research, my MPhil. So I was thinking about, at some point I'll go back to Cameroon, and end up managing some- working in a data management or information management system. That was my thinking. Either you teach it or you apply it, whatever.

When I met my husband and I came to Manchester, I was pregnant, I had my son, I stayed with him at home. I decided that, even though we didn't have any money, my husband was studying, he was doing a PhD at Manchester University, and I thought, I've been studying and working all my life, let me look after my baby. So I stayed at home, but after a year I was going up the wall. And I thought to myself, I need to get out of this house before I kill someone. So I started looking around. And I came across several jobs. The one that caught my attention was kind of like a proxy social

worker. I didn't have qualifications in social work, but it was to do with supporting people who were having difficulties within a faith context, within a faith environment. The Church of England had a post for a community development worker, and it was advertised in one of the local papers at the time, maybe the Manchester Evening News? So I looked at it, looked at the specs, and I thought I could do this. So I applied.

And one of the reasons I like to share this with you - I applied - is because when I looked at the job description and the person specification, they were asking for someone to welcome people in church, to help people who are struggling in the community, to visit them, to assist them to access the benefits and the services that they were not aware of, or they couldn't do it by themselves. And I was brought up to do that. My parents, you know, are very churchy people, and that's what I grew up and saw them doing. And when I was in the Catholic school that I mentioned earlier on, I used to visit old people at home, that was part of being part of that establishment. We used to go clean the church, clean the graveyards, and all of that.

So when I looked at the job description, I thought to myself: they're going to pay you to do this, I've done this, my parents do this back home. And this is normal life. So I applied, and I went for the interview. And when they asked me, why do you want to do this? I said, I'm used to doing this kind of stuff, without being paid. So if you're going to pay me, I'll do it. And I was very honest with them. So I got the job, you know, and I worked with them for three years.

Whilst I was doing the community development worker, it was like I've just explained: supporting people, you know, not just people who are part of the congregation, but those who lived in the Hulme and Moss Side community, in terms of visiting- really we're talking about social isolation: people living on their own, being lonely, and all of that. The church has been doing that for a very long time and still do that. That's what I did, you know, so so many years ago. My job was to visit people. I had a long list of old church members that I visited. And when I went to visit them, when I knocked on their door, they would tell me about another old lady, another young person around the corner, who didn't have any family. I'd go visit them, [ask] how are you today, you know, have you had anything to eat? If meals on wheels hadn't delivered the food that they wanted, I'd sit there and I'd ring them, to say, this person hasn't had their food, or they're not happy with what you're giving them. That's what I did for three years. If they were struggling with completing benefits forms, I'd go through it and ask them the questions, and I'll make sure, then I'll go back and make sure that they're OK. That's what I did for the Church of England, and through that, eh, I met the Queen.

[00:15:31]

**INTERVIEWER:** Really? When was that?

**PARTICIPANT:** Yeah, I went to London, we were invited- oh, I can't remember the year. The Church of England had this "Faith in Community" thing that they did, some big posh do in London. And they invited me to it, so I met the Queen, so I felt really really grand.

[00:15:50]

**INTERVIEWER:** Did you have to curtsy?

**PARTICIPANT:** Oh yes, oh yes, I had to curtsy. You know, and she wore her gloves, and you know, she did ask me where I was from, because from my accent she probably knew I wasn't from here. I said I was from Cameroon. And Prince Philip was coming right behind her.

Through my work with the Church of England, I got to know about other initiatives that were happening in Manchester. And someone came to the Church that – the Church of the Ascension is not far from here – to inform us that they were going to open a needle exchange in the community. People were up in arms, because they thought, dirty needles, they're going to infect our kids with god knows whatever, and this and that and the other. And being the daring person I am, I put myself forward as a volunteer to say, I need to understand what this is about. I never knew anything injecting drug use at all. I think that was my initiation into health matters in that sense, you know, harm reduction, that was what they were telling us that, the reason they're setting up a needle exchange is to give out clean needles so people didn't re-use and share needles, and leave dirty needles around the environment. So they could bring the dirty needles, get clean ones, and they could get advice and support.

And I found that quite interesting. I thought, why not? This is something that we should be doing as a society. So that got me interested. I volunteered, I went through some training, and I started opening the needle exchange on a Monday. They opened I think once a week or twice a week. And I would be there behind the counter - they'd bring the dirty needles and I'd give out the clean ones, take them and put them in a sharps safe and they'd come collect them.

Then, the local authority, Manchester City Council, who at the time were setting up this initiative, decided to bring Black people together to talk about HIV and AIDS. Which I shared with you, when I came to the event, yeah? They kind of like, put on, you know, invited the Black community – back then we didn't use BME, it was the Black community – to come and talk about the impact of HIV and AIDS on the community as such. And they invited me because they knew I was a community development worker, a Black woman, affiliated to a Church, you know, meeting with a lot of Black people - do you want to come to this meeting? So I thought, OK, I'm gonna go.

In the meantime, when I was in London, as a student, they put this leaflet through our doors: "Don't Die of Ignorance. HIV and AIDS." Took one look at it, [thought, I'm] not gay, I don't use drugs, I'm not a prostitute. I put it in the bin. I just thought, got nothing to do with me, just dumped it. And I forgot about it completely. So when we were invited, or when I was invited to attend this meeting, I thought, should I or shouldn't I? I thought, OK, you're doing the needle exchange, why not? So I went to along to this meeting.

Whilst I was there, I could feel the anger, the tension; there were presentations about HIV, a new thing that's come, it's impacting on everybody. The Black community

needs to wake up and take responsibility and be aware of, you know, take on board the prevention messages, safer sex messages, and all of that. I came out of it with mixed feelings, you know. I had my anger, I had my, why should be bother? If you're blaming us, that it started from Africa, monkeys, all of that. And... I still attended the second meeting, you know, I still went along. And there was a call for who is interested to try to get together so we could form some kind of a pressure group. That's how I got into health - through anger and curiosity, I suppose.

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**INTERVIEWER:** OK. Just going back to the needle exchange, where was it based?

**PARTICIPANT:** Hulme.

[00:20:19]

**INTERVIEWER:** What was the building? Was it the church?

**PARTICIPANT:** No, it was an old... oh my god, what was that building? Was it a GP surgery? An old building, you know, in Hulme, in the middle of Hulme, not far from- very very near to the church, yeah, a few minutes' walk from the church. That's where they decided to set up the needle exchange. To be honest with you I could find that out, but I can't remember what the building was being used for at the time.

[00:20:54]

**INTERVIEWER:** OK. And how was that work for you? How was it working there? What did people think of you working there? What... did it bring you into contact with new kinds of people that you-

**PARTICIPANT:** It brought me in contact with people who I had come across my day job in church. People who - parents, particularly, who through drug use, were not looking after their kids, is the only way I could put it. Some of them, I found out that the reason they weren't looking after their kids properly, or they were coming to access food banks- you know, people think food banks have just started in the last few years. We used to run a food bank at the Church of the Ascension, and I was giving out food parcels, and there was a family that used to come almost every other day to collect tins of food. And I used to wonder, OK, you might not have enough to pay for everything, but why do you come here all the time? When I started working at the needle exchange, I think I realised why, because they were using more or less all the benefits money on buying whatever drugs they were using.

I remember a family particularly, because that's one of the most sad memories of my working at the church. Mum and Dad had this little boy who came to the youth club. I was invited to be part of the youth club. And I don't know if you even want me to go into that. I went once, and I told my boss who was the vicar at the parish that I wouldn't do it. Because I came from a culture where the way young people talk to adults is different from the way I watched the kids speak to the youth workers.

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**PARTICIPANT:** Service users who came to collect food parcels, the son used to the youth club. And it was years after, I started piecing things together that, the only time he had something to eat was when he came to the youth club, when we gave them some pizza. He had hot meals at the local primary school. He was a latchkey kid, as I later discovered there was that terminology - there was nobody at home when he left to go to school in the morning, or they were all out of it. When he came home, there was hardly anybody to give him food, and he drowned in one of the local canals. As if that didn't hurt me enough, we rallied round, people collected money to pay for his funeral, to buy him a coffin and a nice little suit and everything. The parents used it. But they were in a bad place themselves. Yeah.

So through that, I got to understand people who are vulnerable, people who are caught up in a system where, I don't know why they were using drugs, but I think it got me to think a bit more about, when we talk about disadvantage, vulnerable, you know, marginalised, what does that look like? I didn't have that understanding to be honest, until I think when I started working in that needle exchange, and I was looking at who came to the church to access the food bank which we were running, and who I saw, I could see a correlation. A lot of the people who came to get the food, you know, some of them were in the community, using the drugs, not looking after kids. Some of them were kind of like, in and out of prison every other... you know, if you didn't see them, nobody needed to tell you where they would be. They would be locked up for petty crime, for stealing, and then when they come out, they'd come to us for some clothing, for some food, you'd help them with housing.

It was an absolute eye opener for me, to start understanding the... difficulties in this society. I was never exposed to that. I came from an affluent African family. For them to send me to England and to be paying my fees, I never experienced that kind of poverty, that level of living before, I never saw it. I'm not saying it wasn't there. I lived with family when I came here; when I studied in London I was hanging around with my students, with my friends. When I got to understand what poverty is like in the Western world is when I worked for the Church of England, when I was at the needle exchange. It was an absolute eye opener for me. And I struggled with it, because the picture that's painted, England is like, how can anybody be poor in England? How can people not have food? How can kids not have parents to be there when they come home from school? That was the first time it hit me. And it really threw me. It really really, it did my head in for a while, before I came to terms with it.

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**INTERVIEWER:** OK. You mentioned receiving the leaflet through the door. I guess that was the first time AIDS was on the horizon for you. And then you mentioned these meetings. At that point in time, how conscious were you of HIV/AIDS being this kind of potential or real threat, or something to work on?

**PARTICIPANT:** Nope. It meant... when I was in London, when those leaflets, those tombstones or you're gonna die of ignorance leaflets came through the door, [it was] totally over my head. It meant nothing. I didn't relate to it, I didn't see it having anything to [do with] me. If I gave it a second of thought, if I saw anything, and it was

linking HIV and its origin to Africa, it made me angry, and I just dismissed it. I just thought, yeah right, yet again, anything bad comes from Africa. I just ignored it, totally.

When it, again, angered me, made me dismiss it even more, was when, as I shared at the consultation event, I came to England, I grew up in a religious family where you do your bit for everybody, for yourself. In Liverpool, the blood donor people used to come around and recruit students. At that age, you're young, you're OK, you can give the blood and blah blah blah. I thought, yeah, why not? So in Liverpool for three years I was on the blood donor register. I'd go give blood. At the unit, they'll come, you'd go into a room and lie there and maybe be reading your papers, and that's it. You step out of there and you think, OK, I've done my bit.

Down in London when I moved, there was something that was going round, you know, there was that leaflet that was going round, if you're from sub-Saharan Africa, you've had sex with someone from sub-Saharan Africa, blah blah blah, you can't give blood. It was a rude awakening again for me, because I just thought to myself, I don't see myself as giving anybody in this place HIV. I don't have HIV, what's your problem? So I just kind of like, said OK. I think I had a bit of a conversation with my GP about it, just lashing out and saying, what the hell is going on and all of that, but I still ignored it and I just thought, OK, just another racist thing that you're going to throw at Black people, Africans, and what have you. It wasn't until I attended that first public meeting in Manchester that I revisited some of the conversations I'd had, some of the literature that I'd read or come across, that it became something that I started thinking about.

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**INTERVIEWER:** So could you say a little bit more about that then, about how you did start to think about it and how you came to get more and more involved in the forum, the network that was set up?

**PARTICIPANT:** OK. After the initial public meeting, where there was so much anger, there was a proposal or a suggestion that those who wanted to carry on the conversation, wanted to do something about it, should meet up, and continue the conversation. And I decided to go to the-

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**INTERVIEWER:** Sorry to interrupt. Can I just ask, was that anger at the first meeting, was it about the way the Council had approached the topic, or was it about the way that HIV/AIDS was described in some of the presentations, or was it the ways in which Black people had been absent from conversations, or been made absent-?

**PARTICIPANT:** It was all of that. It was all of that. The people who organised the meeting, who were working at the AIDS Unit, as it was called, in Manchester City Council, were the initiators of this meeting, right. And because they had a remit to do something about HIV and AIDS. And they were looking around at, you know, the preventative messages, the images that were being put out there, the kind of support

that they were trying to cobble together to support people who were diagnosed with AIDS at the time, because it wasn't an HIV diagnosis, it was an AIDS diagnosis, in those early days. They were kind of like, frustrated, because they felt that on the one hand, Black people, African people are being blamed for this. But when they looked at the messages, when they looked at the programmes and the action plans that were being pulled together, they felt that there was an absence or a lack of recognition that they needed to target a particular community who would be affected by this.

So they came with their own frustrations. But they wanted the Black community both to be aware, and to wake up and to ask some questions. So people went to the meeting, from what I observed, if I can remember right, was that, when working in the AIDS Unit... What do you want us to come and talk about? We are already blamed. And it was a mixed bag of emotions. But out of it came a set of questions. OK, you're blaming us, we're angry about that. What should we do, and how do we do it, and who's going to help us? And those questions kind of precipitated the need to invite individuals who were interested to come and meet and to start seeing how those questions could be addressed. Yeah. And I went to the follow-up meetings, and a pressure group came out of that, and letters were being drafted and sent to the local authority [saying] you're blaming this community, what are you doing about it, you've produced these leaflets that you're distributing up and down the place, there are no images of Black people on it, you don't have any plans for working with the Black community given that you're blaming them for this. So there was a lot that we were challenging, the key commissioners and the key policymakers at the time, within Manchester. It was very Manchester specific, very Manchester focused.

And interestingly, because the people who initiated that meeting worked within the local authority itself, I am assuming, and I would like to believe that, they had started having conversations in house before they called that first meeting. Because the other policymakers, officers within the local authority, came at some point to say, OK, we do understand the frustration, we do accept the fact that we need to do some targeted work with the BME, the Black communities – it wasn't BME, it was Black communities, at the time – how can you work with us to address this problem? So I think they'd been having some conversations in house, wondering how they could deal with it. And some of their workers had decided to call that initial meeting. I think they had started some of the thinking, because they were very forthcoming. I don't think they were really surprised that people were that angry, people wanted to do something. Because it didn't take that long for them to actually give us some space within the Manchester City Council, a desk and a chair, not much but it was something, to say, OK, come and be part of us, for us to start discussing how we deal with this problem. And some of those offices are still in the system as we speak. And still work, and are still supporters of BHA.

[00:34:42]

**INTERVIEWER:** What kinds of people, and how did that then turn into the Forum? Or was that the Forum?

**PARTICIPANT:** I could name names, I don't think they'd mind me naming names. From the local authority's side of things, Michael Naraynsingh, who is today the

chair. We've gone full circle: he's the chair of BHA today. He was very instrumental in pulling together that first meeting. He worked alongside Monica [missed] [00:35:11], was another lady who worked within the AIDS Unit, as they called it in them days. Who else was involved...? Maybe not at that initial meeting, but other key people from the public sector side, you know, people like David Reagan, Bridget Hughes, Mora Noon, Tom Rowbottom, Paul Nethercote. There were quite a few of them, who, right from the very beginning, you know, bore the brunt of our anger, but stood by us to say, OK, but they challenged us to say, we're not sure how to go about this, but we'd like you to work with us to see how we can address this issue. And I think that is a unique model, when you look at the way we work today, that civil society identifies a problem, and the public sector acknowledges it wholeheartedly and from the onset, says, OK, let's work together to address the problem. I think it's something to look back on and feel really positive about.

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**INTERVIEWER:** So could you tell me more about the forum, the pressure group, the network? How did that become...

**PARTICIPANT:** There was a Manchester AIDS Forum, and Manchester AIDS Forum was looking at a whole raft of things. So when we were agitating, the officers that were in the local authority who were members of that AIDS Forum, used to take what was coming out of the Black HIV and AIDS Forum into their conversations. Because from the pressure group, from having the table in the local authority building, we decided to set up as an entity, or an entity was set up, and it was called Black HIV and AIDS Forum. It was very HIV specific, it was a forum. It was a membership organisation, people were subscribing to it, we were agitating, we were hassling everybody and anybody, asking questions, you know: who is going out there to tell the Black communities, the BME, the Black communities, the Africans, about HIV and AIDS, raising their awareness, telling them about it, giving them the messages, how they could protect themselves, the safer sex messages, and all of that. That's what it was all about in the early days. And of course you need people to do the job, you need people to go out there and raise the awareness. We had the desk in the local authority offices; we had our very first funding from, I think it was the National AIDS Trust, I'll have to check that out. But we had some money, to start doing awareness raising, and to start forming ourselves, constituting ourselves and all of that.

I had... When I joined the movement - I call it a movement, however we want to describe it - I was still working for the Church of the Ascension, and I was going to the meetings, and they were looking for volunteers, volunteers to train them to go out and start raising awareness. Because we were then challenged as a forum to say, what are you going to do? And the response was, we need to go out there and raise awareness within the community. And they said, OK, do you have people who want to do this? So whoever was running the show at the time said, who's going to volunteer to be trained? I had no background in health promotion whatsoever, never mind something as controversial and sensitive as HIV! I put myself forward, and I said, go on, I'll go on the training, what are you going to tell me?

So I started off as a volunteer for the organisation, and you know... Manchester Health Promotion Specialist Services, you know... which names do I remember now? Was Bridget Hughes around? Bridget Hughes, Janet Mantel, they worked for the Health Promotion Specialist Services, they had videos, they were doing training, and all sorts of different things. So they provided us with some training sessions; this is what HIV and AIDS is about, this is what it stands for, this is how you contract it, or pass it on, these are the safer sex messages we want to put out, and what have you. So that was my script to go out into BME communities and raise the awareness.

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And I in my naivety thought, yeah, that's OK, you'd go out there and people would listen to you to tell them, HIV stands for, AIDS stands for. Big deal, big fat sweet deal. No. No, no, no. I soon found out, not long after I started doing my volunteering – I was still working for the church at the time – that HIV is a lot more than giving out information to people. That's the simple bit. It's about behaviour and behaviour change. Behaviours that we've acquired over the years and we practice for all sorts of different reasons. So it was a challenge and a half.

I'm all over the place with this... They then decided they wanted someone who would be a Public Education Officer, that was the title of the role or the description or whatever. So they put out an advert, and I oohed and aahed, and I thought, do you want to give up your job that's not so controversial, and go and do this? And I did. So I left the Church of the Ascension - well I applied for the Public Education Officer position, got it, and then I gave up my job with the Church. I had no background in health promotion at all, except the little bit from videos and training sessions that I'd attended, to go into the community and raise awareness around HIV. And to start setting up a project that would support people living with the condition.

[00:41:36]

**INTERVIEWER:** So what kinds of outreach did you do, and what did it look like?

**PARTICIPANT:** OK. I do remember when part of my induction, I was given a list of groups of Black organisations in Manchester that I needed to go and raise awareness with, share information, give out information. There were over 200 groups, BME groups as we describe them today, or Black groups, made up of Africans, Caribbean, South East Asia - we're talking Chinese, you know, Pakistani, all of that. The definition of Black was all-encompassing, it wasn't BME, it was Black, and we were using some definition that had been created by, I suppose, the Commission for Racial Equality at the time. So, my part-time role, it was a part-time position, was to go out to these various groups, and talk to them, tell them about HIV, what it was, how it was transmitted, and tell them about safer sex.

So I was given this list of over 200 organisations, so I ring them, and speak to whoever answered the phone – usually either the chairperson, the coordinator, whoever – explain to them who I was, what my role was, and if I could come when they were having their meeting, or if they could have a session, I could put on a session where I could come and talk to them.

It was a mixed bag. I kind of like, knew it was better for me to be flexible in the way I worked. If they said they'd put on a session for you and it was for 20 minutes, you had to make the most of the 20 minutes. If they said, we usually have our meetings on a Sunday afternoon, we'll give you five minutes, I'll take the five minutes. I didn't turn down anything whatsoever, because I just felt any inroad, once you get talking and people see the relevance the significance, they'll invite you back. Some communities just said, we don't have a problem with HIV in our community, we're not promiscuous, we don't do drugs, we don't have a problem, no. Others were very very welcoming. It was a mixed bag.

So I went from north Manchester to central Manchester to south Manchester, preaching the HIV transmission song, you know: this is what it is, this is how you get it, you can protect yourself by this, that and that.

The reception and the reaction from various groups was mixed as well, as you can expect. Some communities were very very welcoming, accepting, questioning, and trying to connect, because- I had a script linking what was happening in their home countries, like in Africa, part of Africa where HIV was really devastating, causing a lot of ill health, to India, to wherever. So I used some of the statistics. And some of the groups were really interested; they had family, or they were worried about what was happening in their countries of origin, so they'd invite me to come back, and they'd say, come and tell us about what's happening, what work is happening, and how we can help. Others were really not... [they were] either scared or not interested, just thinking, it's nothing to do with us. For some communities it was like, we've got bigger fish to fry, HIV isn't on the doorstep, go away, we'll pick it up as and when. It was a mixed bag, right across. And when you talk about Africans, Caribbeans, Asians, you know, it's a mixed bunch of people with different experiences, different generations, the younger ones, the middle ones, all sorts. It was a challenge and a half. And the responses were just as varied, from very very welcoming, you know, wanted to look into it, deal with it, to, we are not interested. And I think you still... if we say that's not still the case, we'll be kidding. But then, we didn't have social media, we didn't have the Internet the way we've got it today. Then, if you didn't go out there to talk about it, there was nowhere else people could get information. So it was really important that we go out there and raise the awareness, and let people know that this was it, you know, these were the issues.

Early days were really challenging, really difficult. As things evolved and more was known, you preached, you know, you gave the bad news, but you also gave the reassuring: there's medication, if you take your medication and you adhere to your medication, you would be OK. We had people who came to us and said, I've been diagnosed with HIV, I'm at uni, I'm going to drop out, because I know I'm going to die soon. You know, and what could you tell them? Because the number of people that we saw dying, it was a lot. The Church of the Ascension where I worked, when I left to go and do the HIV work, I was there almost every week for someone's funeral from the community who had died from an HIV related condition. So I still had my connections. If it wasn't HIV transmit transmitted through sexual intercourse, it was through injecting drug use. So I was still caught up in that world of health, and a health condition that carried such disturbing social connotations. I was still embroiled in all of that world.

[00:47:49]

**INTERVIEWER:** Before I forget, you mentioned in your scripts, making it more like a global thing in terms of referencing their home countries and the pandemic as it were. I'm wondering how - maybe this is a question for the end - but I'm wondering, often in the UK I feel there's quite a national focus, for understandable reasons, but at the same time, I wonder how having that awareness of the transnational epidemic then shapes your own perspective on HIV/AIDS in this country? Or... it's quite a big question isn't it?

**PARTICIPANT:** I'm not sure I understand the question, but in terms of where people were coming from, I suppose, they will want, you know... if memory serves me right, people wanted to know what was happening in their home countries, because they were suspecting that things were happening that people were either in denial or not so sure what was going on. And they wanted to do something, or pass the message on, that if you don't feel well, go and get checked. They wanted to link back to their home country, you know, to maybe do it a little bit for people to accept that there's a problem, because for a long time, a lot of the countries were in denial, you know, it's wasn't... it's not HIV, you know, they're dying from something else. Countries where HIV was decimating the young, productive population. Families were losing young people. In my home country of Cameroon, there's a section in the graveyard, in the village where my husband comes from, where they describe it as the HIV graveyard, because of the number of [people] in their 30s that died at that particular time was, you know, big! And there was... the need for, maybe not because they could do anything, but there was that denial here, the denial back there, because of that stigma and discrimination. So people wanted to come to terms with it and start relating and supporting people from a distance, if I'm making sense?

[00:50:06]

**INTERVIEWER:** Yeah, yeah.

**PARTICIPANT:** There was a lot of- and there still is, you know... it's now HIV... all of a sudden, in my part of the world, there was a cancer epidemic. No, it's not cancer, it's HIV. None of the families were comfortable to stand up and say, this auntie, this uncle, this person has died from an HIV related illness. Why? Because it had connotations with promiscuity. Drug use in my country wasn't the route of transmission, it was, you know, if you have got HIV, you're a prostitute, you're sleeping around, you're unfaithful, everything but. For that reason, people didn't go for the check-ups even when they were sick, or disclose to any family member. So [if] you died, we found something else as a label for what killed you. And people were trying to say to families back home - go for your check-up, and you're not a bad person, you're not a dirty person, if you happen to get HIV. And with the right treatment, if they pick it up on time, you can start medication and not die before it's too [late], you know, for things not to get really bad. So...

[00:51:22]

**INTERVIEWER:** How do you think that message played in your work here in Manchester in terms of then, people being able, especially BME people being able to

access health services and access treatment or access testing or prevention initiatives?

**PARTICIPANT:** Through the work that we've done, we sensitised and we supported people. You know, we got the community to acknowledge that we were disproportionately affected, if we didn't do something about it, you know, the burden would be heavier than we would like it to be. Go for your test, take your medication, and if you're found to be positive, we can support you or signpost you to where you can get the support. So you can not drop out of university like people did in the early days. You can carry on living a normal life, living with HIV.

We, BHAF as we were known, were very instrumental in raising awareness of HIV in the BME communities of Manchester. We got people talking about it, we got different generations talking about it, we got people to access whatever services, because even when the services were there, people weren't accessing it because they were scared. People weren't going for the test, they were testing late, and some of them still test late. And you just have to keep putting out the message: go for your check-up, these are the routes of transmission; if you're found to be positive, adhere to your treatment, and go regularly for your check-ups. We have been very very instrumental in changing the HIV map, I think, of what it could have been if we weren't here, you know, in Manchester and further afield. And other the years, as the treatment and medication, you know, science has improved, everything, we've made sure people are aware of that, yeah, it's not a death sentence. At one point people just gave up, you know: I'm diagnosed with HIV, I'm going to die next year, next week. No, it's not, you know, go for your check-ups, take your medication, and look after yourself, and you'll be fine. Today we're proud to say, with science and with what we've done, people are thinking differently, that yes it's a long-term chronic condition, but you can still live a normal life, whatever a normal life is, with HIV.

[00:54:04]

**INTERVIEWER:** Can I just ask, BHAF, the F stands for forum?

**PARTICIPANT:** Forum, yeah, it was a forum.

[00:54:12]

**INTERVIEWER:** OK. And when was that officially founded, do you know?

**PARTICIPANT:** 1990.

[00:54:20]

**INTERVIEWER:** OK. I've asked everyone about this- how much do you think people did change their behaviour? I'm thinking maybe particularly men in terms of condom use, or being able to negotiate safer sex in relationships. Do you think that has changed, or...?

**PARTICIPANT:** I would like- because I'm an optimist, and I'd like to justify our existence, I would say things have changed, but different things have changed in

different ways. I would start with condom use. We give out a lot of condoms, and we have different outlets using, you know, Black business outlets: African shops and what have you. And over the years, when we've not been to a particular outlet, they'll ring us and say, we've run out, come give us condoms. So in that sense, people have come to realise that there's something you can do to protect yourself and to protect other people, you know, through the number of condoms and the number of outlets. Because we go to events, we take the condoms, and people take them. People come and they ask us, you know, have you got condoms, we put them out, people take them. Then we have places where we have little condom baskets and things. And the people who own the shops would ring us up and say, we don't have any condoms, they've all gone. So in that sense, people are taking them.

As someone who's done research, the fact that they've taken them does not necessarily translate to they're using them all the time, consistently, and whatever. But it's a start, it's a positive step. They're taking them. Something has computed in their minds that, this is something I could use for one, two, three reasons.

In terms of negotiating safer sex, I have my good days and my bad days on that one. The times when I'll say to myself, if you look at where relationships are and how people are negotiating- not just in this country, even back in Cameroon, in Africa, where I come from, as a woman, the gender thing, you know, has always been a big element within the HIV agenda, negotiating safer sex. Within cultures where you don't even talk about it, how do you introduce negotiating safer sex? You don't. So you're dependent on someone to look after you, financially, emotionally, to look after you, to look after your children, for all sorts of reasons, and sex has been an unspoken thing. You do it. All of a sudden, because there's this virus that's out there, how do you as a woman, go and start talking to this man about, where have you been and where have you not been? Because I'm not saying only men affairs, women do as well, but most of the time, in the cultures that we deal with, the women are in a much more vulnerable position, and struggle to negotiate safer sex.

[00:57:52]

**PARTICIPANT:** If you take all of that and a lot more into consideration, you question: have people moved on? I'd say yes. By how much? I don't know. And yes, I read a lot. I'm an avid reader of research and where people are. And there's a lot of talk about investing in empowering relationships so the dependence on someone for financial benefits doesn't make you vulnerable to being exploited. Things have shifted a bit. I'm thinking all over the place. If you look at parts of... I'm not so sure about England, but I can think about research I've read about different parts of Africa where the World Bank and all the other international institutions, the UN, USAID, and they've invested money, and some of the DfID money, to get vulnerable women who have been dependent on their partners, boyfriends, husbands for money, to look after themselves. When they've given them microfinance to do things for themselves, it's enabled them to become more confident and to be able to say, [if you're] not using a condom, I'm not having sex with you. But before that, if you didn't have the means to look after yourself, what are your chances? What are you negotiating, when you can't feed yourself, you can't feed your kids? You're going to take a risk. And we've seen the devastation of that. But there's been a shift where women are now, you know, vulnerable people are becoming a bit more confident,

because they can plant vegetables, they can rear chickens, they can rear goats, and whatever, and they can send kids to school - all those things have helped.

It hasn't helped with homeless kids, the AIDS orphans. We still see that in a lot of the poor countries where mum dies, grandma has died, and the kids become homeless, they're still very vulnerable - what is their chance of negotiating safer sex? In this society, what is your chance of being homeless negotiating safer sex? You're sleeping in the streets. Someone comes and they're giving you- we know it happens. What are your chances? You don't know what they're going to pass onto you.

So it's still something that the most vulnerable in society are still grappling with, even in the Western world, we're still struggling with that. And in relationships where finance isn't the issue, emotion and wanting to be loved is still an issue. You talk to young gay men, they'll say to you, someone makes me feel loved. You you talk to a young woman, someone makes me feel loved. It's not the financial side, it's wanting to be in a relationship. They might start off by saying, OK, let's start using condoms. Does it carry on? Do they both go to have a check-up before they start having sexual intercourse without... For me it's the biggest minefield. When it comes to human sexual behaviour, it is a big one.

But PrEP, I think PrEP is doing something. If we're not seeing it up north beyond Watford Junction, we're seeing it in London, right? If we're not seeing... condom use, the rate at which people are taking the condoms, to me is telling a positive story, that people are using it more than they have in the past. And we had the highest incidence of teenage pregnancy in Europe at one point. When you look at some parts of the country it's not as bad as so many years ago, so clearly something is happening. Not at the pace at which we'd like it, but things are changing. So I'd like to be optimistic, yeah, that it's changing. Not as fast, but it's changing.

If I've answered that question? I don't know.

[01:01:57]

**INTERVIEWER:** Yeah, I think you have. Do you have any particular memories of the time when you were doing that outreach work? [sharp intake of breath] Wow.

Do you have any... Well, one question and then maybe we'll wrap up. Do you have any particular memories of, kind of standout memories, of over the years doing outreach work and working with people in health promotion? Are there any kinds of encounters, or meetings, or... things that stand out, that you remember from your work? I don't know... For example, earlier you told me about how it affected you in terms of the young man coming from your church, who was being neglected because of drug use and then eventually died-

**PARTICIPANT:** Young boy, he was about 9. There were two of them that drowned. It's one of the saddest things in my life at that church.

[01:03:16]

**INTERVIEWER:** Do you have any other memories, any other kinds of things that made you, I don't know, think different, or changed your perspective, or that just stayed with you?

**PARTICIPANT:** I've got loads, but... There was someone we worked with, very very closely. He was a... he was... [sigh] OK, let me re-think this.

He died. He was very very ill, and asked his minister to come visit. Gay man, gay Black man. And the minister went to visit. And after that, we went to visit, my colleague and I. And he said to us that the minister had been and said to him, you need to pull the ripcord. Which translated into: you're a gay man, which is wrong in the eyes of God; you need to make your amends before you die. I've never forgotten that. That expression, "you need to pull the ripcord". It's stayed with me for a long time. It's haunted me to be honest. This is church, this is faith, this is someone on their dying bed, and this is the message they're giving them.

And when he died, not long after that, his family would not allow the memorial book that was signed at most of those deaths that we attended to be brought there, or his gay friends to make any noise about his sexuality. This is the typical... I'm a Black woman, I'm a woman of faith, and the times when I question how faith intersects with humanity and what it does to our mental wellbeing, and where we leave people and how we leave people feeling, even when they are on their deathbed... Yeah. I believe in a god, but the god I believe in isn't one that will not accept me for who I am because I'm gay, lesbian or whatever. And I'm speaking as a Catholic woman, you know, Roman Catholic faith background. And I do struggle with that every so often. I really do.

And every so often when I'm confronted with this, that and the other, I just go back to that, and I just think: my religion is important to me, my faith is important to me, but it can be just as bad and just as damaging, and it's how we manage that, how we hold the two together. Because for some people, their faith is so profound, y you know. We've met some Asian gay man who've come to us here, and their faith, their sexuality, is a big problem. They struggle, they really do struggle. And I just question, personally, I just, you know... if nothing else, twenty-seven years I've been in this organisation, in this job. It's where faith, health and a lot of things come together, and what that does to us.

[01:07:20]

**INTERVIEWER:** OK. Thank you. My final question is, if you had to sum up to someone what you feel like BHA for Equality has brought to health promotion in Manchester, to services in Manchester, and going back since the BHAF days, how would you summarise that to someone else? What difference do you think it's made in terms of HIV provision, but also health provision/health promotion generally?

**PARTICIPANT:** BHA stepped out, and challenged and questioned, and got the system to listen, and the system to think differently. And on the back of HIV, the system has continued has continued to listen, not just on HIV issues but on other issues. And I believe very very strongly that BHA has been a catalyst for the system to think differently in terms of the health of the BME community, that they

commission, they design, that they provide. We have worked hard, not in isolation, with the system, to say, you need to think about a whole number of things if you're going to be a good commissioner, a good provider. If you're going to design services, if you're going to change things round, you need to think in a different way. We have been very instrumental in getting the system to think differently, and continue to do so.

[01:09:06]

**PARTICIPANT:** One of my frustrations is that there's a lot of evidence in the system, whether it's in terms of access, in terms of people's experiences accessing health and social care services... I'm not saying nothing has happened, but I think we spend far too much time gathering evidence, some of which is already there, and not enough time turning the evidence to make the changes that need to happen. And you get tired, frustrated, fed up. And you think, why, oh why, oh why? You already know - you've been told before. What difference have you made, or what are you going to do? But you keep asking.

**[01:10:01] End of transcript.**