

## Interview transcript: Big Brother

[00:00:00]

**PARTICIPANT:** I come from Zimbabwe, it was 2002 on the 4th of November when I relocated in to this country. On my arrival I claimed asylum at Gatwick. After some time, it was a failed asylum seeker, I was a failed asylum seeker. Then they put us on this other scheme, called Legacy [?] [00:00:44].

[Short silence]

So from that Legacy, that's when they gave me some [Missed] [00:00:57] stay here, it was almost after eight years. Yeah, was I got my stay. I came here in 2002 and I got my stay 2010. So it was a struggle, a bit of a struggle. Anyway, I was under the social services [...] And then, it was in 2003 when I wasn't feeling well, so I went to the doctor, to my GP, then my GP sent me to Fairfield General Hospital. By then I was living in, my asylum house was in Radcliffe. So when I went to Fairfield General Hospital, that is when they diagnosed me, they said 'you are HIV positive'.

From that time, I started taking my medication. But it was a struggle. Before I could meet some other guys, I was called in by my consultant, so he is the one who showed me, told me about George House, that is a charitable organisation which look after people with HIV. So when I went there, I found a lot of people there and it really helped my situation because most of this, I was meeting people who were in the same category with me. So it really improved my health. So I kept on taking my medication until up to now, but it's... through that journey a lot has happened.

I remember one other day, I was sick, my back was paining [?] [00:03:31]. So I had to call an ambulance and then they come, it was early, it was around 4am. So on my way to hospital I disclosed everything to the paramedics. When I disclosed everything to the paramedics, it was like I said something which has never been heard before. They all looked at me, and on my arrival to hospital they went and told all the nurses that, give them the notes and then the nurses read all them notes, that I'm HIV positive. And I was really in pain that time. [?] [00:04:21]

From that time, nobody came to attend on me. It was a four, five, six, seven... it was almost about five hours in the A&U [?] [00:04:39]. Nobody attended me until I... what surprised me is, people who were coming from home, walking, they were served before I was served. Then I started wondering, what was happening? I went to the reception and asked for complaints forms.

[00:05:03]

On hearing that I wanted to write something on a complaints form, then the receptionist went inside, talked to the nurses that this, what this guy is looking for, he's looking for complaints paper. And from that time they called me inside, that's when they started treating me. And they gave me some medication until I went home. Right. I managed to struggle, how things are happening and how we are treated in the hospitals. It was then, in 2008 when my son came from Zimbabwe. He did not know about my situation, nobody knew because I told nobody in my family,

nobody knew about it. Then my son also claimed asylum and he failed his asylum case.

Then after failing his asylum I then, because I had some time when I was depressed, I went to the doctors and they gave me medication of depression. So after that my son claimed on my behalf, that he was the only person that I knew here, that I was living with. So we presented that in to the courts, and I went to George House, they managed to write a letter, a supporting letter. And I went to BHA, they wrote me another supporting letter. I went to my GP, he wrote me a supporting letter. And at first he won the case anyway, but the Home Office applied, went against the case. They appealed against the case.

Then we are doing it again, only to a barrister. Then another second hearing the decision said, [?] [00:07:45] he is telling me the first decision until [?] [00:07:50] I got some papers. It was a bit of a lift to me because I know I have got my son with me here and it was a bit better.

At one time I was sick again, a sore throat. So I went again, I went to this other hospital. Now, before it was... I went to Manchester General Hospital. This was now Salford General Hospital. So when I went there, on my arrival I did tell them again about my sickness. And upon hearing that I was in the room like this, on the bed, and the nurse who was attending me, when he read my notes, he went back in to the other room and told the other nurses who were there. I think I was in that room for about 25-30 minutes. They just left me there, and then now come other nurses to look... he told them that 'he is HIV positive' so they were coming, surprised, they wanted to see how I was looking, maybe they thought I was sick, very very sick. And everyone was just coming for the purpose of seeing me, the guy who was HIV positive. They were about... a lot of them who came in to that room, like they are looking for something but I could see that they have been told something.

And later they gave me the medication. I went. Ever since from that time, you know, you feel that those are the things which really brought me down.

[00:10:02]

Because you know, you can just feel that, what's wrong with HIV? Yet there are so many diseases which are more dangerous than HIV. If HIV right now is treated, you can be living a normal life like I have been living a normal life ever since that, and I have never been in the hospital very very sick. No. Until up until now, I have managed to take my medication on time and it's keeping me well. I am as fit as anyone else. In my brains, I feel I don't have it, it was... it's not affecting me, it's not... you know... everything I am doing, I am capable of doing everything for myself. Up until now I am working, I am doing everything, I am able-bodied at the moment. I manage to control my situation up until now. Yeah, I'm feeling strong.

[00:11:12]

**INTERVIEWER:** Great. Could you tell us a little bit about your involvement with GHT and BHA, the Black Health Agency? What do you get up to there? And also, which we're pausing I'm just going to adjust your microphone.

[00:11:34] [Break]

[00:11:51]

**INTERVIEWER:** Yeah, could you tell me about what it felt like going to GHT or going to Black Health Agency, meeting other people? How did that make you feel?

**PARTICIPANT:** Yeah, going to... firstly I went to George House, I was told about George House, then I went in to George House. I was a service user to George House Trust. Being with them, I just felt, when I met some of the people I felt it was home away from home. Because I meet so many people, they laugh, have a chat with. Another session called the 'African Service' where we could meet men and women both involved in activities. They could arrange us some weekend away. It really had a good impact in my life. And after that now I started volunteering for George House, I was a volunteer for almost four years with them, and I even own an award for Best Volunteer.

I was distributing food parcels and then I was involved again in Community Care where I could visit some people who were affected with HIV in hospitals. A new arrival [?] [00:13:33] they'd, you were talking to them. Upon seeing me, the way I was and telling them that I was also sick like you, and it really helped a lot of people. Confidence, some people had lost hope, but when I talked to them and they asked me 'are you also HIV positive?' I said 'yes! I'm in your situation'. And then the guys I meet them now, I meet them before when they were very sick, but now I meet them, they are strong, they always give me a comment that 'you made a difference to our life, because I thought 'oh, this was the end of it'. If there were no guys like you, otherwise I couldn't make it up to now. But because of you I'm here.' And it makes me feel, it touches my heart and it makes me feel happy when I see someone who was dying on his bed and now is so stronger than me.

Then I [Missed] [00:14:39] again, there was Body Positive. There was Body Positive, the way you always meet there, it really made me, a good difference. Because they could cook us a nice decent meals, every Thursday we could go there and have a nice decent meal, and we could meet our society. It was quite interesting, until it was closed.

Then, now I was involved again with BHA. They had some meetings, we all used to go to some meeting where we could meet with my society but due to lack of funds then they stopped so many activities. At that moment we are still going there, they are giving us food parcels. That makes a difference from everybody, because some of the stuff we get there, we can't afford to buy them. But they managed to give us something which is really good in the society, to have those kinds of groups.

[00:16:07]

**INTERVIEWER:** So what happens on food parcel day, on a Friday? You go along, do you help out? How do you organise it?

**PARTICIPANT:** Yeah, they have some volunteers, about three volunteers, but sometimes we go there, there are a lot of things... carrying which is needed, we go and help them before they distribute the food, we help them pack the food on the table. From there we share the food amongst the people around, and those that are not there, we manage to leave some for the other people who are not there. So we make a very big difference in the society. [?] [00:16:48]

[00:16:53]

**INTERVIEWER:** Something that came up when we spoke last time was that, how the experience of living with HIV can be very different. For example, there were people who were there who were homeless, who were looking for a house, who maybe didn't have enough money to buy good food so they came for the food. How do you think all of these things affect the, living with HIV? Like, if you're also struggling with financial or with your home, finding security, do you think it makes... how does it affected...?

**PARTICIPANT:** Yes, that one alone makes a very big difference in somebody's life, especially if you are homeless, you don't have anywhere to stay. And you are living on hand-outs from people, so you need decent food. Like the way BHA is doing, they are giving us good food. It really makes a very very good impact in society, in our lives, our day-to-day living. Especially with this condition, you need nutrition food. So we really thank this organisation for looking after us and looking after everyone who is in need.

[00:18:45]

**INTERVIEWER:** Yeah, okay. How have you... obviously, if you're not comfortable talking about it you don't need to talk about it, but how have you found your medication since you were diagnosed? Is it... has it been... some people have side-effects, for example, or some people have trouble with the medication. How was it been for you?

**PARTICIPANT:** Right, the first medication I was given, that was... it was good, but sometimes I could feel drowsy. Drowsy. That one was a bit, it was not going well with me I can say. Until I talked to my doctor, then he changed the medication for me. That times I was taking... just forgotten the name. Now I am taking F [Missed] [00:19:52]... the one I am taking now, that one is working wonders with me. I will never feel anything when I take them, I'm just as normal, I don't feel insides pains or nothing.

The last one I remember, I couldn't sleep the whole night. I could wake up, I'd mostly wake up mid-night from that time until morning. I will never ever sleep until I changed them, not I'm comfortable with what I'm taking right now.

[00:20:31]

**INTERVIEWER:** Okay, great. I was going to ask as well about, so this project is also about our relationships, and I was wondering about how, if you could talk about your relationships and whether, yeah, erm... whether, I mean if you could... I guess this project is trying to document, it's kind of about intimacy as well, about the way we negotiate our relationships, yeah. Have you found that easy to do, or quite difficult, or...?

**PARTICIPANT:** Yeah, dating back from a long time I remember when I was in love with this other lady. And someone saw me walking with that lady. Before I was in love with her sister. Before this incident I was in love with her sister. So he knew her sister is HIV positive. Now, she was then deported to South Africa. Right. After some time, that's when I meet this lady. [Missed] [00:22:05] love and then meet this sister of my ex-girlfriend. She now tells us 'you know this man is infected with HIV' to my girlfriend. And upon hearing that, the woman was so angry, she came to me, 'why didn't you tell me that you were HIV positive?' And from there, she went for some test anyway, and they found all the results were clear. Then she phoned me apologising, saying 'sorry, I thought you infected me, blah blah', you know, it was this. 'But I am very sorry' but it was hard for me now to carry on in love with that woman. That's when we had the break-up from that time.

And I remember again one time I was walking with this other lady, I just proposed love to her, we are just starting and I meet some of the people, I always meet them in George House. So those people, again, went to tell that woman that the guy is HIV positive. When I'm... I called the lady a second time, it was a different story. She couldn't continue with me. I could really sense that 'okay, those people I met, they met the lady.' And later she told me about the people, that they told all about me. That is the biggest challenge that we have in our society, confidentiality. We don't have that confidentiality.

Someone might be in the same situation with you but if he sees you walking with another person, with another woman, he tried to destabilise, to get involved. Until now I've got someone who is also in the same situation as me, it's all fine now. I manage to, we manage to get along our lives nicely, with no problems.

[00:24:56]

**INTERVIEWER:** So over the years obviously you have a lot of experience. What would you say to people who are struggling with living with HIV or perhaps maybe who are maybe younger and maybe they don't have a diagnosis yet, but they are, in terms of sexual health or safer sex that kind of thing, what kinds of conversations do you have with people, like? What kind of message?

**PARTICIPANT:** Like I said, if I could get... if I know someone who is in my situation I can manage to change his life as well, because I will tell him according to my experience, I've been there, not to be told... I have to tell him, 'if you keep your medication you will be safe'. The only thing with this disease is you don't have to ignore your medication.

[00:26:06] [Break]

[00:26:16]

**PARTICIPANT:** Because I know a guy, he was diagnosed. Upon being diagnosed he met his wife. They were taking medication nicely and there are some of these religious churches. Then they told him that 'oh, we pray for you, you don't have to take medication any more'. So they followed what the pastor said and then they stopped taking their medication. After a while the wife was so sick and she passed away. Then the husband again was very very sick. At one time he could not move alone, he would move with nurses. They would bring him to George House with some nurses' aid, helping him. But if I tell you the guy's well now, as I'm saying, it's unfortunately that he lost a wife but you can't even tell that the guy was sick like that. He's now fit and strong.

[00:27:50]

**INTERVIEWER:** So before we end, is there anything else that you would like to say, maybe anything that we haven't mentioned, that we haven't covered?

**PARTICIPANT:** The only thing I want to say is like, those who were affected, they must seek advice. Go to the doctor's, see the consultant, they will manage to live their normal life like anybody else. HIV's no more dangerous like, it used to be without medication a long time. But now they manage to get some medication, it's under control. So I just encourage anyone who is in this situation, or to get tested if you don't know your status. Get tested and then get medication you'll be okay, that is the biggest message I would like to pass everyone. Out there I know there are people who are in denial. They need counselling and all that so that they can get proper medication they will be alright.

**[00:29:09] End of transcript.**