

ORAL HISTORY PROJECT

Chronicles of The Lost Decade

A project sponsored by Dira Sengwe Conferences

Interviewee: **Shaun Mellors**

Interviewer: **Angela McIntyre**

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Shaun Mellors

AM: I don't have a structured questionnaire, ok? I think people should be allowed to sort of set their own story telling priorities. But what I do have is a kind of a chronology here at my fingertips so, if you choose to tell a personal story or a story about a political journey it doesn't matter but it'll be nice if you can sort of keep it - keep it in some kind of chronological order.

So what I usually tell people is, start from the beginning. What's your beginning?

SM: My beginning is 24th of December 1986 when I was diagnosed HIV positive, at the age of twenty. I was at the Johannesburg College of Education at the time studying to be become a teacher. It was during the December vacation that I collapse one day at my vacation job and was rushed through to the Joburg Gen at the time. In casualty was asked a few questions by the casualty doctor. She saw that I had a few swollen glands, asked had I had any weight loss. Asked if I was homosexual, and for me it was the great awakening, I could come out publically as being gay and I said – Yes I was – and she went out and came back a few minutes later and said, I'm sorry to have to tell you this but you have AIDS and about six months left to live. And that was how my story began.

AM: With a death sentence?

SM: With a death sentence. At the time there was very little in South Africa in terms of HIV organizations, in terms of any type of counselling services, I recall that I was referred to Prof Reuben Sher at the South African Institute for Medical Research which was one of the first HIV centres in the country for some type of counselling. And the first two years of my HIV diagnosis I was literally waiting to die and every time I saw something in the media about a person with HIV looking very thin, very frail I was anticipating that I was going to become that person.

I think I also made the faithful error of telling my university lecturer that I was HIV positive at the beginning of the new academic year, and he went to the Vice Chancellor and told the Vice Chancellor who went to the Chancellor and they had a meeting and called me in, and said they do not think that an AIDS victim would be able to teach children, and thought that it would be a good idea for me to leave, and enjoy what time I had left.



AM: Is that how they said it?

SM: Yeah, yeah, yeah.

AM: Do you remember sitting there when you heard those words?

SM: At the time I believe, at the time cause in the media HIV was a death sentence, HIV was there was no future, people with HIV were not normal members of society, at the time there wasn't anybody who was public in the country about being HIV positive, and so all I knew about HIV was what I read in the papers what I saw on TV. I think Rock Hudson passed away two years before that. I think he died in '84 or '85,

Yeah And that's my kind of image of that, but I believed them and I left which for me was very difficult, because I mean ever since I was "this high" I had wanted to become a teacher and it was my greatest passion, uhm, to become a teacher. And of course when I left university my parents wanted to know. "But why are you leaving, you've always wanted to become a teacher, it's what you were dreamt about?" And I couldn't tell them that I was HIV positive at the time. So I made up some story, that it's not what I thought it would be, I wasn't very happy so I decided to leave. Much to their dismay as well, I think that they were very surprised and very hurt.

AM: Did they get angry with you?

SM: My father got extremely angry, because "All the investment in education and your breaking your dreams, and why are you doing this, and I don't understand, you've always wanted to become a teacher, so that was very difficult, and that was very painful.

AM: Had you come out to your parents at that stage?

SM: I had come out to my parents as being gay.

AM: Ok, yeah alright.

SM: Which was something that wasn't spoken off, because I think my father kind of always believed, and still does believe that I'm going to meet a nice blond woman, and settle down and get married and...



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AM: Just meet a girl?

SM: Yeah exactly, and life happily ever after.

AM: No I was asking because I mean it would be quite significant, I mean those are two things to disclose to your parents and it would be a horrible time.

SM: I think it was harder for me to disclose, well, I'll talk about my disclosure in a minute but, I found the whole process of disclosure to my parents a lot more difficult than I found disclosing that I was gay. But at the time in South Africa, there wasn't, this was now 87 / 88 there wasn't anybody who was public.

And everything that you saw in the media was linked to people looking very thin and very frail. The government at the time, which was obviously the Apartheid Government, was doing very little about HIV. And I remember them having the *Yellow Hand Campaign*, which I think had something to do with, *Stop AIDS*, and they had this horrible yellow hand.

AM: I think I remember that one.

SM: Yeah and uhm, and MandaHolmshaw who was at the time the Director of the HIV program with Doctor Rina Venter, who was this horrible Minister of Health, who wore crimplene outfits and had her hair in a big bun, which was quite something.

AM: This was sort of what '89?

SM: Yeah, yeah. Uhm, and they, uhm – Amanda actually contacted me because I was rioting to them and said – saying to them, what are you doing about HIV? There's no public awareness; nobody really knows what's happening about HIV.

AM: Was that your first letter?

SM: Yeah

AM: What made you write that letter; I mean what made you not retreat into obscurity and accept your death sentence?



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SM: I think because I could not identify with the way that the media was portraying people with HIV. I was not thin or frail, I wasn't dying, I didn't have signs or symptoms. And I think there was an intrinsic need to respond to being defined as a victim, as a helpless victim, as a victim who was busy dying, as a victim who was guilty, as a victim who was slutty, who was a prostitute and being able to respond to all those issues.

And I think that's – and also meeting two other people with HIV who had cycled from Joburg to Cape Town at the time. I can't remember their names. But they had cycled from Joburg to Cape Town, and were supported by Mrs.. Wendy Ackerman of Pick & Pay. And Pick & Pay has been one of the companies who got involved in HIV and AIDS very early on in the epidemic, especially Mrs.. Ackerman, I think she was a real pioneer and she also had a role to play in my development as an activist, and I'll come to that in a minute.

AM: Pick & Pay, the Ackerman's? Ok, I had absolutely no idea about that.

SM: Yeah, so, and that's how I then wrote to the government at the time and said that they had to do something more about HIV. And Manda Holmshaw contacted me and said – Are you prepared to help us? Are you prepared to get involved in an advertising campaign? So that we can show how a normal person with HIV lives and how a normal person with HIV looks. I was obviously very conflicted at the time because it was the Apartheid government, but I just saw what HIV was doing, number one to the gay community, and HIV was also beginning to move into the black community, and there was this kind of sense that AIDS was going to be the broom that would sweep society clean.

AM: There was a lot of that coming from, also from right wing Christian groups.

SM: Yeah, very much. No I think they were struggling because of partly what was happening politically at the time. Look this was 1991. '92 so there was change in the air, so they had to be seen to be doing something. And that's when they had this idea of having an advertising campaign which involved people with HIV. Which at the time was fairly progressive, I think for them.

AM: Surprisingly so.



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SM: Yeah, and they hired a huge PR company to come and take photos. I was living in Cape Town at the time, and they said, Oh it's just going to be a very small photo which would appear in the Department of Health newsletter and maybe in one or two magazines, which would be a picture of you, and showing your story.

There was absolutely nothing like informed consent or any implications of what could happen or would happen with disclosure if you would come out, so I just thought, well I'm doing my cause, I've been arguing with them that they need to do something and I participated.

And I'll never forget the day, it was a Sunday. I was at the pool in Seapoint, with a couple of friends, and I bought the *Sunday Times*, as I always do, and I was flipping through the *Sunday Times*, turned over the page, and there was a full page me staring at me from the newspaper.

And it said; "Shaun Mellors, 24, loves to travel, great sense of humour. And in the bottom said, completed his two years in the army, which was a lie, has AIDS. Does not know how long he has to live. And I still have a copy of the newspaper article. Look it was in The *Sunday Times* and the *Rapport* which was the Afrikaans newspaper, the Afrikaans Sunday paper. And it was also in a number of magazines.

AM: So wait, wait – I have a picture of you standing there looking at yourself in the newspaper, you're probably wearing your swimsuit.

SM: My swimsuit, sitting on the grass with friends. Suddenly the picture comes up. I obviously closed it, but it was too late, I mean they saw it. What was more painful I think, was that that's how my parents found out that I was HIV positive, and my entire family, and part of my mothers' side of the family is extremely conservative and very religious and very "verkramped". So for them to read in the Afrikaans newspaper that one of their family members have "Vigs" it was traumatic, and some of them haven't spoken to me since, or to my parents because of the shame it had brought on the family.

But that taught me a very valuable lesson in terms of disclosure, because although it was my choice, I wasn't aware of the consequences, and there's I think in any disclosure it is obviously a choice, and there's always consequences, positive or negative. And it then became



for me an important issue to ensure that I would be able to change the attitudes that I had encountered, from that article, from friends and family. My parents initially had not wanted to talk to me, they were shocked. How could I bring on such shame to the family? I was fortunately in Cape Town and my parents were in Joburg. So I couldn't just climb into a car, or they couldn't just climb into a car and come and see me. But that in itself was then also an impetus to carry on doing what I was doing to bring about that change.

AM: Shaun that's the kind of thing that makes people commit suicide. I hate to point it out to you, but how did you, I mean how did you weather that? Just thinking, I mean, you know the, just the, I don't know, that's mind boggling. Sorry I'm interrupting your story with some trajectory about your emotional state.

SM: Yeah, I mean I don't think suicide at that time crossed my mind at all. It was an intense feeling of shame initially, and that's also how Mrs. Ackerman came into my life, because Mrs. Ackerman also saw the newspaper advert. And at the time, one of her employees who belonged to our support group was in the Somerset Hospital who busy dying from AIDS.

And that's how I met Mrs. Ackerman, because she came around to the hospital while I was visiting Jonathan. And she said that she saw me in the newspaper, if there's anything that she can ever do to help me, I must just let her know. And a few months later there was the opportunity to attend an international conference for people with HIV, which was the international conference for people with HIV in London.

And I was up until that time a kind of lone crusader within South Africa doing public talks to companies, doing road shows with Prof Reuben Sher, traveling around, talking about the victim with HIV and getting all the "oh shames" and "how does it make you feel" and "when are you going to die" and it was literally that kind of road show. And people not quite sure how to respond when you talk to a group of young students. And you could see the discomfort – But I'm not like you, so I'm safe. It was an incredible, incredible time actually, because while trying to be public there were also people within our circle of friends who were dying because there wasn't any treatment. And there was a deafening silence around HIV, because we were so focused on the changeover, we were so focused on what was going to happen with the New South Africa, all that was just taking up so much time. So I mean the ANC Health Desk before



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the takeover through the Progressive Primary Healthcare Network, started working with us to organize the first NACOSA. At the time it was the National AIDS Conference of South Africa.

AM: Yes that was 1992.

SM: Yeah, and in – But let me first get back to 1991, because that’s when I travelled to London. I contacted Mrs. Ackerman and I said to her. “Mrs. Ackerman, I need to get to London, because I want to attend this international conference.”

And she contacted her travel agent and she sponsored my air ticket and my accommodation in London. And I flew on *Sebina*, was that the Belgium airline? And my first time ever that I was traveling overseas, and it was huge excitement, and I travelled to London via Brussels and it was this most amazing experience of my life. There were five hundred other people with HIV from all over the world, all together.

AM: I imagine you didn’t have to be the poster boy anymore?

SM: Exactly and just talking, sharing, being able to feel as if you belong as oppose to feeling like a victim. And I believe that conference was my turning point as an advocate and as an activist. Because I came back more inspired, I came back determined and I came back with a fighting spirit to ensure that we do something in this country.

And so I got involved with the Progressive Primary Healthcare Network and at the time *Nkosazana Dlamini-Zuma* and *MantoTshabalala* and *Olive Shisana* were all part of the Progressive Primary Healthcare Network and in the lead-up to the planning of the NACOSA meeting, I mean we’d have the meetings in these posh hotels and they’d all come and sit with us and at the time you could smoke anywhere. And I was a smoker at the the time and Nkosisana always said, “Shaun I will only come and sit with you if you quit smoking, if you don’t smoke.” And at the time they were so committed, they were so passionate about doing something about HIV. You could rely on them; you could depend on them because there was this sense of solidarity. It wasn’t sympathy, I mean there was a real commitment, and a real earnest sense of, - *We will put this together.* –



At the time I was working at the AIDS Consortium with Edwin Cameron and Mornè Cornell, and we had developed the AIDS charter on the rights and responsibilities of people living with HIV. So we were going to have a big launch of the Charter and we were going to lead into NACOSA. The PWA “Movement”, for want of a better word, there wasn’t a movement at all in ‘91/’92. There was a group which I cofounded with Johann van Rooy and Noel Pillay called, *Body Positive*. It was a very small group, Joburg based, of predominantly HIV positive gay men, who came together. Who would care for each other, feed each other, and visit each other in hospice.

And then the NACOSA conference came about, and they, at the time it was “hip” to include a personal testimony of a person living with HIV in any conference program. And it was always a personal testimony; there hardly ever was a person’s name, or who they were or whatever. And I shared the stage with Nelson Mandela at the time, who was, it was just such a mind boggling experience. That was the first time that I’d met him.

AM: He was about to become, this was before he became president.

SM: Yeah, NACOSA was in ’92 and he became president in ’94.

AM: Can I just ask you something, had you had any sort of political inclinations before this. You were studying to be a teacher, did you identify with any political party or did you sort of think, maybe I should join the ANC or...

SM: I grew up as pretty much a typical white South African boy, with mixed parents -as in English, Afrikaans - completely protected by my parents and by the system. I did not hear the word apartheid until about Standard 8, so I was 15/16. I did not understand the implications and consequences of apartheid until my final year at school and until I started university.

AM: And then you found yourself sharing a stage with Nelson Mandela?

SM: Yes.



AM: Is that something else you had to disclose to your parents or were they really politically liberal?

SM: No, unfortunately my parents are and always have been very conservative, politically.

AM: Ok.

SM: So when at university I became politically more aware and asked them questions of what is apartheid and who is Nelson Mandela. It was almost shock horror, how can you mention that in this house. And that was for me very difficult.

AM: It sounds like you were a shopping list of disappointments to your parents?

SM: Oh yes, yes yes unfortunately I was. And it continued for a few years after that, but yeah. No it was a big.

AM: So there you were, I'm sorry I diverted you a bit. But you were saying you were on the stage with Nelson Mandela, and you were going to tell me a bit about that?

SM: I mean it was the big conference to draw up the part of the national plan for South Africa, post-apartheid government. And there were two slots for people with HIV. It was myself and a young guy called *Paulus Dladla*, who could hardly speak a word of English, but he came from Kwazulu Natal, and he was willing to be open about his HIV status. I have no idea whether he's alive still, where he is, or whatever happened to him. He spoke in Isi-Zulu at the conference and I translated his speech because we worked together it was a very short five minutes, talking about the impact that it had on him.

And then I also gave my presentation. I can remember very little about what I said, I remember that I became very emotional towards the end of my presentation. I remember a complete standing ovation from the audience and I remember Croatia Abdul Karim coming up on stage who was supposed to talk about the epidemiology of HIV in South Africa at the time, immediately after me, saying, "*Shaun, how can I talk after you?*" And the rest was a blur. I have tried to find my speech from the NACOSA archives; unfortunately I'm not sure whether they have any of those initial papers. So I would like to remember the things that I'd said, I mean I know I took a long time on the speech.



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AM: There must be people around here who remember your speech?

SM: Croatia, Slim, Edwin they were all there. Jerry, I think he was there as well.

AM: Ok, so this was a lesson in the power of testimony for you?

SM: Yeah, it was for me incredibly, incredibly powerful.

AM: So you suddenly found yourself home?

SM: I had an identity, I had a place, I was affirmed, I was no longer a victim, I was no longer the person just in the media.

AM: A medical oddity.

SM: People knew me more, I mean they understood my emotions, I recall the presentation beginning something like.

Name: Mellors Shaun.

Age:

24.

Crime:

Testing HIV positive.

Description: White

homosexual male.

So it was as if I was in a court case, and the audience was my jury, and I was kind of presented to the court, and my crimes against humanity, so to speak. So it came from a very personal place, because then there was not necessarily the need for accountability because I was not representing anyone, there wasn't an organized movement at the time. So having personal testimony was appropriate, it was relevant, it was very powerful.

I learned the accountability as we became more organised as a movement, as we became more structured, as we had to have elections to nominate the chair and the vice chair and the treasurer and all those aspects. So that was '92. I think in '93, I might get my dates wrong, but in '93 the people with HIV representatives on NACOSA, because I now had a seat on NACOSA, I was affirmed as "A person with HIV representative" on NACOSA. We asked NACOSA for funding to organise a meeting of people with HIV.



And we organised the very first meeting at the Tropicana Hotel on the beachfront here in Durban. There was about 80 people with HIV from all over the country, black and white, who came together to become organised. We wanted some kind of structure. Edwin Cameron came as a guest speaker because he wasn't open about his HIV status at the time, so he came as a guest speaker. A few of us were aware that he was HIV positive but also understood the struggle that he had about coming out with HIV. And at the end of the conference, we had our first election. So who's going to be the representatives of people with HIV and amongst the conference participants we had the elections, and I was elected as the chair of this new organisation of people with HIV.

And that's when we tried to become more organised as a movement with the establishment of The National Association of People living with HIV. That's what the body became known as – NAPWA – But in true South African style, there was a splinter group that was formed, I think it was called Positive Living, or Positive Life. Vincent Veal was the person who started the splinter group. And that interestingly enough is how the PWA Movement has almost remained fractured and splintered and I'll talk a bit about that further on in my story with the almost split of the Treatment Action Campaign and The National Association of People living with HIV and AIDS. In '93 there was again *The International Conference for People with HIV* and that was in Acapulco Mexico, which was again a wonderful experience, and as the chair of the National Association I was allowed to attend on behalf of South Africa.

AM: There was funding for that?

SM: That came from *The World Health Organisation* actually the majority, and actually from one of the drug companies. I think it was, I'm thinking *Glaxo Smith Klein* but that's not what they were called at the time, the people who made AZT it was them. At the time it was only mono therapy that was available which was AZT's so they also sponsored a bit about it. And at the Acapulco meeting I was nominated onto the board of *The Global Network Of People Living With HIV*, which had three representative from Africa, Asia, Latin America and Caribbean.

So all the Africans that were there, they got together and they nominated people. And I then spoke to people with HIV in South Africa and we decided to put in a bid to organise the 1995 Conference for People with HIV. And we were granted the bid, and from the 6th to the 10th



of March 1995 - I'll never forget those dates – we had one of the most amazing conferences and experiences, I think, in the history of the PWA Movement.

AM: That was the year of changeover.

SM: Exactly, it was the year after the changeover, the international community was dying to come to South Africa. There was this great sense of euphoria amongst all the participants, I remember sharing the opening stage with *Thabo Mbeki*, who at the time was the deputy president, and *Nkosazana Dlamini-Zuma*, who was the Minister of Health. At the end of my opening speech, at that conference, *Thabo Mbeki* came to me and hugged me plus I was emotional as well. I can be a bit of an emotional freak; well I was a bit of an emotional freak, not anymore. Thabo Mbeki also said at that conference, that an injustice to one is an injustice to all, we must all fight HIV.

So in 1995 he was deeply committed to HIV. He believed strongly in the principles that we were all trying to fight for, which was inclusion that HIV causes AIDS, that people need support, that people need care, and he gave a fairly good speech at that conference. And somewhere in the archives it is on film, I think the photographer *Gideon Mendell*, has got loads of photographs of the conference. We even got *Kenneth Kahunda* to come to the conference, because at the time he had just come out about losing his son, so he also came to the conference. And we had this, we had the quilt project on the lawn in Seapoint.

AM: So there was a South African quilt project?

SM: It was part of the International Quilt that came, but we do now have a *South Africa Quilt Project*, it's not as effective unfortunately as the international one was. But then we had these memories of all these dead people on the lawn amongst all these rich apartment blocks and all these grannies and grandpa's were coming walking along the beach. "*Oh what lovely quilts, what are these about?*" "*Oh it's about dead people.*" And there was shock and scandal and horror, and it was really incredible for me. So at the time there was commitment from government, there was commitment from Dlamini-Zuma in terms of ensuring that people with HIV had a place and that there was support for people with HIV.



And then after that conference I then left South Africa, because I was appointed as the Executive Director of the Global Network of People Living with HIV and AIDS. And that's when I moved to Amsterdam from 1995 to 1999, when I was in Amsterdam. So what happened post '95, I was obviously involved from a distance as the head of The Global Network of People Living with HIV and AIDS. And that's when *Peter Busse* took over The National Association of People Living with HIV. A lovely, gentle, sweet, amazing man who I miss dearly.

AM: Everyone knows Peter right, I mean everyone seems to know Peter.

SM: Yeah, he was just incredibly wonderful and special. But also at the time, *Zackie Achmat* came to The National Association of People Living with HIV this was post the Cape Town conference, and it was talking about the need for The National Association of People Living with HIV to become more activist, to have a treatment activist program. I think it was actually post '96 because all the drugs became available at Vancouver conference it was announced that drugs were available.

And at the time the The National Association of People Living with HIV, as I understand it, felt that they could not become to political, and that's when the split was even more reinforced, and the TAC became more of an activist organisation, became more focused on issues of treatment, trying to mobilize become more of a social movement. I came back to South Africa in 1999 to work on the International AIDS Conference which was going to be held in July 2000.

AM: Let me interject here with a question. Were you aware that during your absence antenatal prominence went from 2.1% to 22% , it's a tenfold increase.

SM: I was aware that there was a huge increase in HIV, at the time I wasn't paying much attention to antenatal. I think when I left South Africa, and I'll have to look at the statistics, I think there was something like two hundred thousand people living with HIV. When I came back in 1999, it was two point four million, so it was this huge.

AM: Tenfold increase basically.



SM: Yeah, and it was for me first, have they got better at reporting or understanding the issues. But in between those five years I'd obviously met up with activists at International AIDS Conferences or I'll meet that cow, *Manto Tshabalala Msimang* at conferences, and I always knew she was drunk, when she came up to me and hugged me.

When she wasn't drunk, she'd walk straight past me and ignore me. But when she was drunk; Shaun – Big hug! Come running up to me and give big hug wherever she was, when she was sober no.

AM: A boozy hug from Manto?

SM: Yeah, vodka smelling, yeah. Which was just incredibly nauseating.

AM: Ok, that was 1999, so she was appointed Health Minister in 1999, when *Thabo Mbeki* was elected. So you were presumably not just speaking to her on boozing hugging terms?

SM: Probably, I mean the speaking terms came from the NACOSA days, where we would sit around the table talking about the National Strategy, what we were going to do the different interventions, how we were going to have an impact, and then in the run up to the South African AIDS Conference, The International AIDS Conference in South Africa, I had a lot more interaction with her and The Department of Health. And at one of the press conferences during The International AIDS Conference, she came walking into the press room.

And I was standing at the entrance of the media room, and she was obviously sober, because I mean she was nasty. And she said, "How, you are still alive!". And I said, "Yes I am, and it's because of ARV's". And she said, "Those things are going to poison you." And off she went to the head table. And the I also saw one day on a plane, flying between Joburg and Durban, and I had a conference bag with all the companies' logos on it, she pointed her finger at me, and she said, "You and your people, these drugs are going to kill you."

AM: Your people? Who did she mean by your people?

SM: Other people with HIV. Because she painted all people with HIV with the same stroke, people who are on treatment.



AM: Ok, so she distinguished between people on treatment and people not on treatment?

SM: Yes, because people not on treatment were poor, they needed her help, she needed to make decisions for them, she had to provide them with answers to their problems. The empowered ones, not important to her.

AM: You were political sell outs if you took the drugs? Did you have the inkling at that point that this distinction she made between people not on the ARV's, that there was a political division within the Department of Health, that it was a division that was going to divide the country eventually, did you have an inkling that this was the situation, I mean this was still 2000?

SM: Yeah, I mean it was 2000 during the AIDS Conference. I knew that there were problems in the Department of Health already in, I think, 1996 or 1997, I'm not sure. When *Nkosazana* was the Minister of Health and the whole *Sarafina* scandal, and at the time Croatia Abdul Karim was the Director General of the AIDS Program, and she left the program in protest at what was happening within the Department of Health. And I have had, and always have had a great deal of respect for both Croatia and Slim. And when Croatia walked out, then I knew there are serious problems within the Department of Health. And I also heard about the *Virodene Scandal* when I was overseas.

AM: Oh right, yeah.

SM: And that's when they were trying to poison people with HIV with this whole new drug. And there's a fascinating story around that whole Virodene Scandal and the involvement of *Thabo Mbeki* and the ANC and so it's really interesting to look at that part of our history.

AM: I heard pieces of that actually, again you know they told me about a situation where top people in the Department of Health were really not being filled in. I mean these policy decisions were being made unilaterally by the Health Minister.

SM: In the organisation of our conference there was complete blockage from The Ministry of Health, even from the Presidency at the time. Because that's when *Thabo Mbeki* pulled together this presidential council on coming to a consensus on what is the link between HIV and AIDS,



and that is when he invited all these dissidents to be part of this council. So all this was happening in the lead up to Conference, and the international community was saying, “We can’t come to South Africa because the government does not believe that HIV causes AIDS.” Apart from the international community saying that Africa can’t organise an international AIDS conference.

So in the beginning of the conference everyone was saying it was going to be a flop, you can’t organise it, it’s not gonna happen, nobody’s gonna come. But fortunately people voted with their feet. And the AIDS 2000 conference was the turning point for treatment in the developing world. Because when people left this conference, it was no longer a question if, but a question of when treatment is going to become available in the developing world, and especially in South Africa. And people often forget the, that powerful aspect of the International AIDS Conference in Durban.

AM: A paradigm change?

SM: It was a huge, I mean so big. Even the International AIDS Society and the international scientists that were here, I think even the South African government then realised, because soon after that they started getting the treatment guidelines, and things slowly started changing.

AM: That must have been for minister Manto the laying of battle lines?

SM: Oh sure, that’s when all the court cases came. The Nevirapine court case and the challenges with the treatment action campaign. I mean the highlight for the Treatment Action Campaign was also the AIDS 2000 Conference, it was for them an incredible affirming, powerful process when they organised the Treatment March at the beginning of The International AIDS Conference where *Winnie Mandela* was marching with them, all these international people were marching from the Durban City Hall to the AIDS Conference here. Where they just refused to receive any memorandum about treatment or whatever, so the conference, I think it was the Conference Chair Persons who actually received the memo.

And during the AIDS Conference when Nkosi Johnson was coming to do a press interview, and that cow was walking down the passage, and I was holding Nkosi hand together with Gale Johnson. And she came up to him and said, “You naughty little boy.” Because of



what he had said the night before about that pregnant woman should be given Nevirapine, if his mother was given Nevirapine he would be healthy and whatever. And the poor little child was just, tears in his eyes and this woman was just, pointing her finger going, “You naughty little boy, how can you say those things?” And it was just, she was weird, she was sick at times, she was scary. And that’s what I remember about her at the AIDS Conference.

AM: She frightens small children and animals.

SM: I think also big people, not just small children and animals.

AM: Ok, so the battle lines were drawn, what then?

SM: And it took a long while to bring about that change. It took treatment guidelines were developed in 2004, which started the big roll out of treatment. And she hated it, she hated that she had to roll out treatment.

AM: *Nono* gave me a picture of her, sort of her with tentacles, basically obstructing everyone.

SM: It’s a very good description.

AM: Ok, you talked about the split between...

SM: TAC and NAPWA

AM: Did that still persist or did they come together.

SM: It still persisted, I think that the movement of people with HIV in South Africa was very fragmented because during this problem with the Minister of Health, the TAC was obviously taking her to court, was obviously fighting against her, while she was coordinating with National Association of People with HIV. So she was getting her affirmation from that corner, she was giving them loads of money. Says, “Go and implement programs cause your good people, you aren’t fighting against me” So all the grants for mobilisation for people with HIV went to the National Association of People with HIV. Some say there was a lot of corruption there. I tend to agree with it, because they never accounted for the money, they’ve had leadership for the last ten, fifteen years which has never changed. And that reinforced the split between the TAC and



the NAPWA because TAC had a cause that they were fighting for, and NAPWA were in the pocket of the aggressor.

AM: What was her agenda if it wasn't treatment?

SM: I'm not sure, you'll have to ask them that. I think at the time it was for them more an issue of becoming mobilised getting people to access grants. And they did that fairly well, they had a very good grassroots and structure. And they were very good at advocating for social grants for people with HIV. So that is to their credit one of their achievements, and they also managed to organise and mobilise people with HIV to a certain point. So they were fairly good in aspects.

AM: Ok, so the National Association of People with HIV and AIDS, were they sort of taking in Manto's doctrine of nutrition and lifestyle?

SM: Yes, very much. Which was also a flashpoint for the treatment action campaign because they were reinforcing the doctrine that HIV is not necessarily the cause of AIDS. It's poverty, its malnutrition, it's all the things the government at the time were saying. And I think that's partly why they were so successful in getting social grants because you need to live healthy; you need to be able to eat properly.

AM: There's nothing wrong with you know, addressing social determinants of health, but there's also no need to reject medicine at the same time.

SM: Yeah, but I think people do funny things when you are vulnerable. And at the time treatment wasn't available for many people with HIV in the public health care sector, it was available in the private sector. But if your body is, I'm challenging myself as I say this, but if your body is riddled with candidiasis you are getting very thin and very frail, you kind off grasp onto any straw.

And if somebody says you must eat beetroot and garlic and lemon juice, or drink certain substances, you will do that. And if somebody says I can give you lots of money to organise yourself to set up chapters in every province. I can sort of understand why they went that way.



In hindsight I think it's a load of crap, I mean they should have argued and fought against it. But thing is, as human beings we are very funny people.

AM: It's interesting, I didn't realise that there was that sort of institutional support. So you kind of have had the "*street fighters*" vs. the "*lap dogs*".

SM: Yeah very much, there was a load of that, and she promoted it to as much as she could. And that's also why TAC was often excluded from policy decisions or discussions that took place. Because she had her lapdog, and so The National Association of People with HIV would give the rubber stamp of approval, saying, "People With HIV support this."

AM: Yeah, besides that I remember them being openly confrontational.

SM: Yeah.

AM: That conflict, I mean that political conflict in some ways I almost see it a little bit as characterising the political culture of South Africa, it's the competition and it simmers and simmers and builds, and there's bloodshed, and afterwards there's a kind of, some sort of resolution and reconciliation.

SM: Well, I'm not necessarily sure that there's been, I don't think that the tensions between NAPWA and the TAC have been ironed out, even today in 2011. I think that the leadership of NAPWA is problematic, because they've been in office forever. They aren't elected, they were appointed by the minister, but within the chapters, there are some collaboration between the TAC and NAPWA. And at the positive convention we had last year, there was an attempt to bring the different groupings of people with HIV together. But it hadn't happened.

AM: It's still the historical grudge.

SM: Yeah, it hasn't. And that's why, when we talk about the new sense of activism, until there is this inspiration again, or until there is this common cause which everybody can identify with and agree with, I don't think there will be a unified movement so to speak. And it begs the question, is there a need for a unified movement?



AM: I wonder, because things happened when there was a “lapdog” and a “street fighter”. I mean do we need that dynamic in order for things to move forward, does there need to be somebody snapping at the heels of government who is outside of the government. This issue co-option really worries me because it seems the inevitable fate of activists that they take up the lapdog position.

SM: But I think it’s partly also a problem of defining activism and understanding that there’s activism and different levels. Because I think many people in South Africa have the concept of activism, is fighting against the government. And that’s their understanding of activism, so now when the government is providing treatment and the government is playing nicely, what is activism about, how do we define activism again. Because we have everything, and I think treatment has had a huge impact on activism, it has taken away that sense of urgency. It has taken away that sense of passion that I’m dying, my friends are dying, I need to be angry, and I need to fight for treatment. But now I’m ok, I have treatment and my friend has treatment, and I can’t make too many loud noises in case it’s taken away. I’m comfortable, I’m happy. And I think that it’s what’s happening with activism internationally as well, it’s not just South Africa.

AM: You know, I think unfortunately activism movements have a lifespan, and I’ve seen this with other campaigns. *The Landmine Campaign, The Arms Control Campaign*, what happens is exactly this process of co-option, because you know, government sign on to whatever protocol it is to stop things, to combat. It becomes that wall; they come up against a wall. It seems that the life cycle of campaigns.

And one of the reasons for that is, I think, when you achieve your target. After that you have to start asking difficult questions, you have to ask, well what about the social determinates. And you immediately put yourself into a confrontational position again with the government over issues like education and gender and so on. It’s like you said, I got my treatment now, I don’t want to lose it over making too much noise.

SM: And that’s also what I refer to as, activism on different levels, because if I look at our treatment program, and I see our clients who are prepared to sit in cues for eight or nine hours. Who are prepared to take lousy treatment from healthcare providers, and I say – “prepared to take” – very lightly, because I think there is a need for individual activism. That those people,



the clients in those situations, have to find a voice to bring about change. Because it can't just be, Section 27, and the TAC who talk about the big picture activism, or the big picture campaigns. Change happens on that individual level, where that person or that woman finds the courage to open her voice and say, "I am tired of sitting in this cue for six hours."

AM: Creating a demand.

SM: Yeah, and I think that we have taken that for granted, as an activist community, that everybody is informed, and everybody is mobilised and everybody's educated, and everybody's aware, they're not.

AM: How would you, I mean can you make some sort of connection between the AIDS struggle and service delivery protests, do you see some potential synergy there? Because there's mobilisation happening there, people are articulating demands in ways that government understands. They're brushed off as instigators and trouble makers. It's coming from somewhere.

SM: And I mean, service delivery protests is trying to address very basic needs of people. The AIDS struggle was trying to meet very basic needs of people. So yeah, I think there is a clear connection between the service delivery protests and the early AIDS protests.

AM: We've diverted your chronology of your story.

SM: Oh its fine, I've changed from an activist to becoming a retired, cynical, jaded politician a few years ago.

AM: Do you feel co-opted?

SM: I don't feel co-opted, I feel disillusioned.

AM: Why?

SM: The movement both in South Africa and internationally became driven by personalities, became driven by personal agendas. And we kind of lost sense of what it were that we were doing. I was just getting "gatvol", I was just getting tired of fighting with diva's and big personalities and one stage I was becoming a diva myself and a big personality myself, and I just



thought – I can't do this, this is not me - And that's when I just decided to take a step back. And it was hard for me; it was something that's affirmed me for all these past twenty six years or whatever.

AM: Not just affirm, but defined you.

SM: Yeah, and now all of a sudden I'm...

AM: You were bloody good at it.

SM: Shaun the healthcare manager who's having a bit of an identity crisis. And that's, what do we do with old retired activists? Because sure there's always activism in me and I think the person who spoke at the end of that session defining the difference between activism and activists is critically important. That activism will always be in me, but an activist, I mean I think it's important to be able to differentiate when it's appropriate to be an activist, and when it's appropriate to be a politician or a diplomat or a manager. And I've learned that over the years.

AM: You've learned to be everything see I haven't. When I reach that point of disillusionment I find that I need to find a new cause. When that phenomenon of personalities and politics take over, I feel like.

SM: Yeah, I think it was a process of survival, a process of understanding the environment, and understanding the landscape and what needed to be done. Because even with activism, activism in 2011 can't be what activism was in 1988 because it's a very different type of activism. It has become very professionalised, which is also something a few activists say that it is a profession. I mean it takes years and loads of money and loads of investments to create a Mark Haywood, or a Shaun Mellors or a Zacky Achmat, it does not happen overnight. And all of a sudden we expect everyone to be well defined, articulate activists, so to redefine that entire agenda, also isn't gonna happen just overnight. It is going to take new people, new investments, new ideology, new thinking to move it forward, and there has to be that sense of urgency. I don't see any sense of urgency in trying to define a new agenda.

AM: Do you see complacency?



SM: Yeah, oh sure.

AM: Taking things for granted.

SM: Yeah, and that's what happened with treatment, I mean, people with HIV have become complacent.

AM: Think about your grandchildren.

SM: God forbid.

AM: Studying to be social scientists, or doctors and they're doing something on sociology and politics and HIV back in the twenty first century. And digging through the archives, they find you, great-granddad Shaun, "Groot Oupa".

SM: "Oupa Grootjie"

AM: "Oupa-Grootjie" Shaun.

SM: "Oupa-Grootjie" Shaun.

AM: And what do you want to tell them, what would you like them to know about the few million people who just vanished of the face of South Africa over this very short period of time, what do you want them to know about it?

SM: I think that we failed, that we failed them, as in the people who are no longer with us. And that it was genocide, and it's hard to explain or justify genocide, because you are often not aware that it's happening until after the fact. Or if you are aware that it's happening at the time, it's very difficult to do anything. Because you are fighting for your own survival, you are worried about what's happening, you are fighting against the system.

And I somehow relate it to *Auswitch*, and people being put in the gas chambers. So many of those stories are never going to be heard, or never going to be told and they've just become a number in South Africa's HIV epidemic. It's become a graph, but they are somebody's "Oupa-Grootjie", or somebody's father, or somebody's mother, or somebody's



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brother. And I think that it is a very dark, sad part of our new democratic history. And history will judge us harshly; it has to judge us harshly for that because it is very sad.

AM: Thank you, thank you for that.

