

ORAL HISTORY PROJECT

Chronicles of The Lost Decade

A project sponsored by Dira Sengwe Conferences

Interviewee: **Pierre Brovard**

Interviewer: **Angela McIntyre**

Date of Interview: **09 June 2011**



1 | **Interview:**
Pierre Brovard

AM: And we're rolling.

PB: Speak in a normal voice?

AM: Yeah, speak in a normal voice.

PB: Cause I'm tempted to project so you can hear me.

AM: No, think of it as a conversation and try not to ...

PB: Try not to look at the camera?

AM: Now you can look at the camera if you want if you want.

PB: No don't give me permission, give me instructions.

AM: Instructions, no, I'm not going to give you instructions because this is a dialogue, ideally it's you...

PB: Talking a lot.

AM: Telling a story about where you were in the struggle against HIV. You know this project is called *The Second Struggle*. Cheeky I know, but I took it.

PB: Ok.

AM: Usually what I tell people is just to, start from the beginning, so eh...

PB: So whatever my beginning is.

AM: Yeah, what's your beginning?

PB: Well I think, sometimes when I train students, which is a lot of work with students which is a lot of what I do on the campus and enjoy very much. Is to say that I came out as a sexually active person and gay man, in the late 1970's which is before AIDS. So I had the privilege in a way of starting on my sort of sexual journey in life, and my identity journey prior to this fear of HIV, this thing that sort of loomed over us from the early 1980's.



2 | **Interview:**
Pierre Brovard

And it's quite a unique perspective to have, I think, I suppose since beginning is before AIDS because there was a sense of freedom and lack of fear, although at the time South Africa was in the grips of apartheid and life was segregated, racially primarily. Although gay lives did manage to cross those boundaries. But I remember the worst thing was about being found out, or be entrapped in some way, or being prosecuted under the immorality act, you know which governed sex across the colour line as well as sex between two men or two women. Maybe two men, I think, not sure about two women.

So AIDS just wasn't part of my reality, and those are the disco years. *I will survive*, so you know when the young kids today dance to the remixes they think this is a new song, I'm always vaguely amused. And then the early 80's I think, starting to hear about this new disease.

AM: It was called the *Gay Cancer*.

PB: Ja, or *GRID* as well. It was Gay Related Immune Deficiency, was one of the early technical terms formulated by doctors in the US. But I started dating somebody in I think 1981, when I came to Pretoria for National Services as it turns out. I was a product of two years of National Service and I was twenty one at the time. And the partner that I met then and subsequently was involved with for about five years, travelled a lot. He loved international travel, particularly to New York, and I think, you know, through him, I already became to get a sense of this, this was quite scary.

And one of his very close school friends had immigrated to the UK, and subsequently became HIV positive before I think a test was even available. It was just called AIDS, by then it was called AIDS. And I remember he came to South Africa when he was probably in the last stages of AIDS. And he was clearly very ill. And it was just; I suppose it was just associated with fear, death, panic, anxiety. You know, not knowing what to do or whether you were affected, and I think in way, we somewhat felt protected in South Africa because although people were traveling internationally, it wasn't as easy and there was a sense that it was a disease of America, or maybe to some extent the UK. But not Africa yet, you know?



But I mean, I think it became very clear that it had come to South Africa, in the White gay male community. Particularly people who travelled, and then of course it would, you know flight attendants or people who had resources and money, disposable income.

AM: What did you see that made it clear, can you remember anything in particular when you realized that this was here in South Africa.

PB: This is really dredging back in my old long term memory. I suppose just people who were ill. Never mind that the news headlines started to filter through the *Gay Plague* and the horror and the doom and the gloom and the pictures of men with *KS lesions*. But you know it became clear that people we knew, either in your immediate or further friendship circles were infected. I mean this friend, I think his name was *Ivan Cohen*, I may be wrong, was the first person I think that I met, that I knew absolutely had AIDS, and I do remember feeling incredibly distressed by the experience. He seemed very, very afraid; at that point I hadn't started my training as a psychologist. I was just someone who had in fact started working for a small Gay & Lesbian helpline in Johannesburg, this was in the sort of, round about '83, '84, somewhere around there. So I was already interested in the counseling, and reaching out I suppose to people who were troubled in some way. And it was a very small, very modest little community run service which was operated at night between seven and ten.

AM: This was in Pretoria?

PB: Johannesburg, by then I'd moved to Johannesburg after my National Service.

AM: Whereabout in Johannesburg was that?

PB: Where was it located?

AM: Yeah.

PB: That's a good question. It moved around a bit, I think it was in Berea for a bit, and then it was in fact in Hillbrow. I remember going into this terribly little seedy one bedroom flat in Hillbrow, were we would council from. Just you and a telephone, you know talking to people who thought they might be gay or lesbian or you know had relationship difficulties, or they're boyfriend was beating them up or something.



It was sort of the early 80's period. And one of the persons who I trained with at that time to become a counselor, subsequently developed AIDS.

And I remember we formed a small support group for him. In fact there was even a little initiative I think, there was a, flowed out of this Gay Counseling service, it was called *The Gay Advise Bureau*, I think, or *GAB*, as in "the gift off". And this guy developed AIDS and we formed a small support group, informally for him, and I think subsequently as I said, it sort off, they tried to form, this organization tried to form a more consistent outreach kind of offering. We did things like go to his home and tidied up his house and his garden, and did chores and formed rosters. I mean at that stage there were no treatments, there was just nothing really except I suppose attempts to manage symptoms and offer palliation of some kind. But I think my overwhelming feeling about that period from the sort of early, middle, late 80's was a feeling that slowly people were just disappearing and dying, and that the gay community was truly being besieged by AIDS, you know.

And it had a terrible sense of democracy about it, seemed to cross all lines and classes. And people who were beautiful and rich, got HIV just as much as people who were not. And it almost felt like the community was imploding, I mean with hindsight I'm trying to remember how I felt at the time. But a profound sense of fear, a bit of sadness and a loss I think started to sort of creep into people's conversations and into your consciousness and even into your unconsciousness I suppose. This anxiety about AIDS just being around. And then I think in the late, round about 1987 or so, think just before I started my Masters training in psychology which I think I started in 1988, I met Peter, Peter Busse, who may have come up in some of these other conversations. And Peter you know, was one of the, I suppose the most inspiring people to meet at the beginning of your own journey in the field. Because he had an incredible charisma and charm and ability to reach out to people and to connect. I think that was probably the most profound part of him, that people could resonate with, was that he, he just connected.

Was it *Auden* who said – "*Only connect. As if your life's script. If you only connect, it's the best thing you can do in life, or the most profound expression of your humanness.*" And Peter had that down to an art, I mean he just connected with people. Black, White, young, old, gay, straight, everybody loved him. I mean he was sort of universally adored.



That changed, I mean some of the politics of AIDS in South Africa meant that at some point Peter, I think, diverged with some of the directions that some of the AIDS activism was going. Not because he didn't support it, but because I think he just felt that there were different ways and different agendas and he became unpopular in some quarters, but never the less I think he, with some difficulty rode that out, and remained incredibly important to lots of people.

AM: I just want to pause you there for a second; you just started talking about AIDS politics, defining beginning to AIDS politics in South Africa. You went from a personal level to going on about a political situation. Do you have a memory attached to that?

PB: I think the politics are of different kinds and of different levels, because I think the overwhelming response to AIDS in the gay community was a community lead response. I mean mostly I suppose by white, mostly men, gay men because the organizations with themselves segregated. I think that became more problematic as time passed, different kinds of gay men were affected and infected and I think the services and programs didn't manage to straddle those divisions. But in the beginning it was, all the responses were from within the gay worlds and for the perspective of the state, it was clear that they weren't going to do anything about it.

So for me that was already a political gesture of ignoring the epidemic in the gay community. I mean I do remember very clearly the Minister of Health, a female Minister of Health, I can't remember her name, Rina Venter maybe, said "This is a problem for the gay community and it's not a mainstream issue. It's not a problem that South Africans in general are affected by. And the gay community needs to look after itself." You know there was no sense that there were any resources going to be put to this at all.

And I think towards the late 80's the other politics that started to creep in were round the fact that the first really proper HIV clinic in South Africa was run at the Johannesburg Hospital by some pioneer doctors who were both gay men. I think *Steve Miller* and *Dennis Sifris* were the early pioneers along with *Reuben Sher*. Reuben wasn't a gay man, in fact he was a, basically a Jewish grandfather, who had gotten interested in immunology because he had a son who had some immunosuppressant illness, not HIV. And he's been in the US and come back to South Africa with an understanding that AIDS was affecting the gay community, he was also one of the early people who got involved.



In fact he helped set up on the first AIDS Training and Information Centre, and I think they were called *Attics* in Braamfontein. And it was through that attic and its work that I began to meet *Peter* in the late 1980's because he got somehow attached to them, and we were overlapping around counseling. I think we were beginning to offer some of the first HIV test counseling in that time, because the test was identified in 1985. So already tests were beginning to be available here after that, and that's where Peter and my lives started to overlap, through the *AIDS Training and Information Centre* in Braamfontein that *Reuben Sher* started. But I think Reuben and Dennis and Steve Miller were the early pioneers in trying to treat and test the people who were affected and coming forward who were gay men. And fighting with government for space in the hospital, fighting for staff.

Is it too much, too little, in terms of my pacing?

AM: No your pacing is perfect, you're a wonderful story teller. Where were we?

PB: I was just saying that they were fighting when Reuben and Dennis and Steve, were fighting for the right to exist basically, to have this clinic. Because I mean the stigma was huge, AIDS had its own stigma's and of course homo-sexuality was still illegal and so there was this clinic primarily for gay men. I mean a lot of those people who were using that service were working class white gay men. But not exclusively, but mostly because if you had private health insurance you went to see Steve and Dennis privately, you didn't go to...

AM: Why do I have so much trouble picturing white working class gay men in South Africa, I can't formulate a picture of that. It seems so incongruent with South Africa.

PB: I seem to remember a lot of them were Afrikaans white gay men as well at that time.

AM: You mean openly gay, I mean not you know ...

PB: No I mean clearly very much, no they weren't all Afrikaans, but I do remember that being a feature of it partly. So when I'd started my Master in '88 and then in '89 part of my internship, I worked in the Johannesburg hospitals, I chose to rotate through the clinic as part of that six month block that I wasn't in Johannesburg Hospital. And it was also a very bleak experience, I just felt pretty powerless. I mean I was just a beginner therapist and felt like, that



7 | **Interview:**
Pierre Brovard

the disease was just so immensely powerful and depressing and pervasive and shocking. I mean because we were already seeing all those extreme symptoms that can come particularly as your immune system gets more and more compromised.

I don't particularly think I did very much good work at that time to be honest, I mean it just felt like you were stabbing in the dark trying to support people going through something horrendous. I do remember though, even then, there were other people who came to the clinic who were not gay. I remember vividly counselling an old white couple, where the one partner had been infected I think through a transfusion, and then had infected his wife, and they were I think, a bit like – *Toto I don't think we're in Kansas anymore* – moment for them, you know. So feeling you know, themselves feeling other, having an othering disease, but being in a clinic which primarily aimed at helping gay men, and they were an elderly hetero-sexual couple in the same clinic. So they were really out of place.

And even then I remember the demographic. There was hint that the demographic of AIDS were beginning to shift, that there were some Black South Africans who were hetero-sexual, some of them from overseas, coming to the clinic. I suppose as that moved into the 90's the issue of returnees coming back with HIV also began to be part of the story which you know was another strand of our AIDS epidemic that I think is sometimes forgotten. The people who lived in exile, and for good sociological reasons we were unable to have stable home and family and relationship lives.

So that period, I suppose, I'm just trying to think of to signpost this narrative. That period of the sort of late 80's was really a lot of hopelessness, a lot of despair. And really not being able to offer people much in the way of treatment or anything that would meaningfully change their lives. I think I mentioned this earlier in the session, where I recalled that at that time in the late 80's, we were saying to people - Don't test, because there are no treatments. That HIV stigma is incredibly entrenched and scary. So don't test but make sure that you use a condom and you look after your health. And do all the exercise and stress management and stuff.

So basically we said, everybody should treat themselves as if they were HIV positive at that time. You know testing wasn't wide spread and it was sort of a strategy at the time, in a way



it was probably appropriate. That knowing you got HIV when you can do nothing for the person, except some early experimental attempts to try and deal with the different symptoms.

I think was probably an adaptation that made sense at the time or a strategy that made sense at the time. And now we're in a position where the session I just chaired, an ethicist presented a session, saying that at a theoretical level, making knowing your status mandatory, is ethically justifiable. She said, we can't force people to have the test or force people to disclose the test. But you can basically make it mandatory for them to have an annual HIV test and keep information to themselves if they want to. But that ethically, given that the treatment is available and people have the right to health, they can only access that right, if they go and have an HIV test.

So this is something about how far the debates have come and gone. And then I started working, had a bit of an hiatus in the late 80's when I, no it wasn't the 80's sorry I'm wrong. I started working more formally in epidemic in 1990, sort of full time; I was still completing my Master's degree. But I started to work in a Hillbrow based AIDS program, it was essentially the Johannesburg City Councils AIDS Response and it was an absolutely fascinating period to be involved in a formal way in the epidemic, because we were based in a building that was in Esselen Street. Which became widely known as a really innovative, comprehensive sexual health program. We had an HIV testing service, we had TB, we had contraception there were STI treatments there was an outreach program to sex workers and gay men, all of us were employed by The City Council and we were all trying to work in an inter-disciplinary, integrated way in this one building.

Even ran an evening clinic for people in the area, in Hillbrow, who couldn't come to these services during the day, Thursdays there was an evening clinic. So it was a fascinating time to be doing this work, and it was really ground breaking work. I think the fact that it was so integrated, made it quite unique at the time. And we had the status of an *ATTIC, an AIDS Training and Information Centre*, of which by now there were beginning to be many more around the country. These were municipal focused HIV Responses, and they were often the core of the work that was happening.

AM: So this was around 1991?



PB: Yeah there about.

AM: Ok the first antenatal services was 1990.

PB: That's right, I think the prevalence was less than 1%.

AM: But then there was this point where it was discovered that hetero-sexual transmissions and MSN transmissions were the same.

PB: That was I think was in the early 1990's and I suppose that's just a function of numbers really. The percentages were higher in gay and other MSM and other gay men, but...

AM: Did it change the politics at all?

PB: Well I think that the indifference to the gay and MSM epidemic continued. But I think the fact that it was affecting hetero-sexuals as well added a new flavor to the debate and the discussions. And as I guess was the build-up to the NACOSA process, which was round sort of between 1991, 92, 93, somewhere round about there. Which was sort of the nationally coordinated consultation process which brought ANC health desk.

The ANC hadn't been formally unbanned at the time, but it was, I think *Manto Tshabalala* in fact was one of the key persons at the time. And had a very different reputation of being progressive and an important figure then in helping to bring all these parties together. I remember being part of the team working on the counseling strategy with Peter, *Peter Busse*. We co-wrote some of the counseling strategy in the very beginning. So I think what the hetero-sexual, the realization that there was the beginnings of a hetero-sexual epidemic wasn't greeted with urgency that it deserved. Because we could have probably had a different trajectory for the epidemic if we had intervened differently then.

But there was still a lot of denial and resistance, and I think the fact that we had the contrast of the MSM epidemic seeming to be primarily white gay men, white persons, and that the hetero-sexual epidemic was beginning to be evident in black South Africans, you know the seeds for interesting racial and sexual dynamics were already sown then in some ways. But there was a lot of excitement about the NACOSA process and the bringing together people across the political spectrum. So it was an interesting period of, I suppose synergy and agreement and



consensus building, and this plan which was essentially the draft that was presented to the first ANC government, was a pretty good one actually for its time.

But I think was easy to forget that the grouping who were working on it were represented a lot of progressive voices, and that the broader population was largely probably quite ignorant of AIDS, A, and B, probably quite judgmental, you know and stigmatizing that it was still very much a disease of the “*other*”. It was still seen as a disease of gay men, or sex workers or drug users, and then I suppose constructed as a disease of blackness as well.

AM: Tell me; was there any sort of synergy between the Anti-Apartheid movement and the first AIDS activism? Was there any connection because I’ve spoken to a couple of people who come from essentially conservative backgrounds, who suddenly found they didn’t really have a trust in politics, who found themselves somehow affected and associated with the AIDS struggle in the late 1980’s.

Who found themselves sort of mingling with people who were terrorists, and enemies of the state. We talked about the cross over and the sexual dynamics, but now there were also political issues.

PB: I think that’s true actually, and now that you mention it, it seems so obvious that is what was happening. That idea that, it forced people into the same room, who wouldn’t otherwise be in the same room. And I think some really interesting things started to happen as a result of that. It was a vehicle to say, well there is a new common struggle which can unite us, and bring people from different worlds together. I don’t know, my first response to your question was, did you mean people who in anti-apartheid moved out of the country? But I think inside South Africa yes, absolutely, yes that is what began to happen.

AM: You know Shaun said something very funny yesterday, well not funny, it’s quite serious. But he said because I was asking about him disclosing and coming out to his parents. First he had to come out as a gay man, the he had to disclose his status to them at some point, and then there was the fact that he was standing on the same stage as *Nelson Mandela* and he was from a conservative political background, so it sort of was like a third disclosure. I found it really fascinating, the political dynamic.



PB: It's true and I think, if you just think about the NACOSA process itself, it brought together so many different people from diverse backgrounds.

And if I think about the program that I worked in, I mean we were working, it was very racially mixed in terms of you know, gender and sexual orientation. So there was a sense of, we're just breaking out of all the kind of boxes. And really looking at the fascinating diversity of who we were and that team was already a statement in itself. I think ahead of its time really in terms of crossing those traditional divisions. I think the person who ran and started that center in Hillbrow that I mentioned was a doctor called *Clive Evian* who had a history of being in sort of progressive primary healthcare network and being interested in community health issues, you know from a very young age.

So he brought in a sense his political and struggle credentials to the AIDS arena, and I think that infused into our center, our thinking about trying to root locate HIV in a social understanding, rather than just seeing it as about individuals who had unsafe sex. And that really was very important, and I think quite soon after that he paired up, with my current boss, who I met then *Mary Crew*, who was sort of a sociologist and historian from Wits, and I think she added to that sort of sense that AIDS is as much about our political and social past as it is about sex today. The whole sort of way in which Apartheid configured the South African population made so many more people vulnerable in millions of different ways.

AM: What I find fascinating is that in South Africa still seems to, it keeps its, I like the metaphor of the *cordon sanitaire*, but we haven't gotten rid of it, it just keeps moving around, shifting around.

PB: I think there is an irony about that, because there were a lot of questions in the beginning. Why did South Africa's epidemic seem to take off later in some ways than epidemics of other African countries. And I think there was a sense in which our borders were not as porous and the fact that apartheid isolated us, and when the *cordon sanitaire* was as much enforced from the outside as it was from the inside, and so we were sort of held at bay from the epidemic and vice versa. Obviously the fact that people traveled and moved around across borders did happen, and then ultimately internal migration has been as much of an issue as anything else.



But it was almost as if the conditions were all there and when the virus came, it just exploded out. And you can see that antenatal graph that just climbed dramatically from 1990. So those early, the 1990's now I suppose where I'm still locating my narrative. We'll be here till four o'clock do you realize that. I suppose if I try to sum that up.

AM: We can do a part two later.

PB: Oh good.

AM: I don't want you to feel like you have to squash everything in, we have an hour.

PB: And we've been going now for?

AM: About forty five minutes, but we'll come and find you again, for now carry on. We're in the area of NACOSA. *Soul City*, do you remember *Soul City*, it's been around for a long time, I think 1994. Did you have anything to do with that?

PB: Not formally as in working for them, but over the years we've had associations with *Soul City* and at times been consulted on campaign messages. But I think the *Soul City* idea of *Edutainment* as it was termed, was something that took hold. And I remember when I worked at the city council in the 90's we developed a drama with council workers which went, an AIDS play essentially, which went around to whole ranges of City Council municipal employees, and it had a sort of gender violence theme and sexual agency which was, I suppose you know, quite progressive for the time. Had a little black cast some of whom ultimately, I think one of the actresses is now acting in *Isidingo* as *Ma Agnes, Keketso Semoko*, worked for us at the time. You know so she helped, so she was one of the early people getting involved in AIDS theatre, *Puppets against AIDS*, I think that became *AREPP*.

A lot of interesting stuff in for the media we were developing at the time was fascinating I think. You know, posters and plays and we had comic strips for gay men, which we put into gay publications and just a lot of interesting stuff, sex worker clinics and all that was happening in the 90's when I was working in Hillbrow on that project.

AM: That's a whole archive in itself, where do we find out about that?



PB: I don't know, I've got a little bit of that stuff, I don't know if enough of it's being archived.

AM: There should be a collection of that stuff.

PB: I think the comic strip was called "Save my Mate"

AM: Do you have copies of that/

PB: I might have ja, I think I tried to keep stuff at some point.

AM: That's an exhibition there, the early AIDS activism.

PB: Absolutely, so I suppose from a political perspective those early, the early years, I mean the *ATTIC* system was in place and there was a National AIDS Program, but I think that the implementation of the NACOSA plan was not great. Particularly the in the *Mandela* years, were characterized by, from his perspective, quite a lot of silence around AIDS actually. He didn't make it a key of his presidency, I think he was more about nation building and trying to reach across divisions and looked towards the future and AIDS coming into that mix was not desirable, not palatable and not part of the reconciliation plan, to be honest.

AM: It was kind off over shadowed.

PB: It was, I'm trying to remember who the health, it was, was it *Nkosazana Zuma* was one of the early Ministers of Health under *Mandela* I think. And then there were those sort of, *Virodene*, *Sarafina* scandals or *Virofina* scandals as I call them, because they somehow were the terrible twins. The idea that you know you could have an AIDS drama, which cost a lot of money, I think *Mbongeni Ngema* was the playwright who got lots and lots and lots of money, that hasn't changed, he's still getting lots of money to do stories. And the play was kind off, I think aesthetically it was very pleasing, lots of singing and dancing and happiness, with the thread of AIDS woven into it and perhaps very simplistic or moralistic messages.

But it just, you know, I mean, it's not going to change people's material living conditions or the reasons for them getting involved in unprotected sex in the first place. And there were scandals around tendering, and waste of money, and it was a mess frankly. And then *Virodene*



was also terrible, it was seemingly this rogue scientist from the University of Pretoria, decided that this industrial solvent had shown some promise in some laboratory test and pretty soon without I think ethical clearance, were testing it out on poor people, some of them, most of them Black.

AM: On the military?

PB: Subsequently, but then it was Mozambicans who were coming to South Africa or being recruited. Because Olga, what's her surname? She was Portuguese speaking, she was married to an Afrikaans man I think because of the language, maybe they were sort of migrant laborers.

AM: Some expendable people.

PB: Yeah, well pretty much

AM: Reminds me of *Project Coast*, do you remember the project, did you ever hear about the project?

PB: Coast?

AM: I'll tell you about it someday.

PB: Ok. think I may have mentioned the other day that I had a client I was counseling the other day in the sort of middle to late 90's, around the time of the Virodene stuff, who'd actually took Virodene, the patches. He had traveled to Pretoria and he was prescribed them by Olga and her team, it didn't make a difference. I mean he died, he was already very ill, and going blind with CMV retinitis at the time. So he was desperate for something, and this probably predated the use of AZT or AZT wasn't working either.

But I think from a political angle, the fact that it was clear that they were getting money, I think they were getting money from the cabinet to do some of that research and it bypassed all kinds of ethical norms, checks and balances. And I think it sort of raised debates about, we need an African solution. I think *Mbeki* was in the cabinet then already, this threat around Western medicine is experimenting on Africans, and we need to find and own our own solutions. Not



only from traditional medicine perspective, but also there could be cures and treatments that are located in Africa, which African scientists need to own.

So in a way by thumbing their nose, is that the right expression? At the Western medical establishment, by doing the whole Virodene thing, they were practicing on poor black people, without proper medicine control council checks and balances, I don't think it was approved by any ethics board.

AM: Yes it was extensively more acceptable than taking western pharmaceutical colonials.

PB: Ja, and I think leading into the Mbeki era, you know that became entrenched in those years. You know I think that was probably the most difficult time in the fight against AIDS, because it really felt like the AIDS establishment, which was mostly good people trying to do good work, were at war with the minister of health and the president.

And there was a lot of maneuvering and tempting to do work, in spite of and not because of the State, or the government should I say, or key figures in the government. I mean looking back on it now, it was kind of bizarre what happened, you know there was that *Castro Hlongwane* document which you've probably come across, you know which was this incredibly long rave, and I think *Peter Mokaba* might have been implicated in writing it or been involved in it in some way. I mean he subsequently died of AIDS as did...

AM: He was apparently the ghost writer, that's what I heard.

PB: And then subsequently *Parks Mankahlana*, who was also Mbeki's spokesman died of AIDS, and it was the disease that dare not speak its name, but in a new way. You know that, you couldn't say that people were dying of AIDS, because the very fact of AIDS and its link to HIV was questioned. "How can a virus cause a syndrome?" he said, you know, Mbeki very, very clearly.

And I remember him quoting research from medical journals in parliament. And saying; "Here look, they say there are these terrible side effects, these are poison." But what he would admit, I seem to remember was that, the conclusion of the journal was in spite of the side effects, the drugs should still be administered because it would ultimately save lives, and he was



selectively reading medical texts. And I think it, just before or around the time of the 2000 AIDS Conference here in Durban, which was the International AIDS Conference, which was hosted for the first time in South Africa.

He set up the Presidential Advisory Panel on AIDS, you know which was a mixture of dissidents and regular scientists. I think *Peter Deusberg* might have been one of the early ones. You know it was just a bizarre attempt to say, well can we get consensus building approach to science, doesn't matter what the evidence says or, you know, you look at it and you vote and the winning vote wins in deciding on whether HIV causes AIDS. People didn't know what to do, I mean you know, people were dying.

AM: Did the bizarreness of it really strike you then, because sometimes you know, things only seem truly bizarre in retrospect. I mean at the time did you know that *Thabo Mbeki* was wondering around the internet late at night, picking and choosing, because that the notion of that to me actually is really horrifying. That the most powerful person in the country is deliberating on a matter that he knows next to nothing about, I mean did the full horror of that sink in?

PB: I think it did, I think people were horrified and from an international perspective we were embarrassed by what was going on. I mean people were horrified, there was a lot of despair and hopelessness and anxiety, you know and anger. People were really pissed off and upset about what was happening. And I think that the rise of the TAC can be seen in the light of those years. That something has to be done. And TAC's ability to mobilize, to be grass root spaced and to have a very strong political agenda rooted in rights and strong legal support was just very much in parallel with those early years.

AM: Some people suggest that, uhm, I mean that's kind of what consolidated democracy in South Africa as a test, the first real test of the constitution.

PB: It was, and I think also the idea, you know perhaps the first time that there was a sense that civil society elements could be at odds with a democratic government. That idea that this is a government of liberation, that largely has a support for everybody but it has been challenged within its own ranks. So I do think that was really, it was quite a fraught time and allegations of disloyalty, un-patriotism.



And if you read some of the stuff that Mbeki wrote at the time, I think also that what for him was very difficult was the idea that the epidemic could have taken such hold of Africa. And he interpreted the fact that people wanted to present these statistics and present the difficult stories of AIDS in Africa, were not motivated by racism or by a view that African people essentially are sexually promiscuous and cannot control their sexual appetites.

AM: I think the phrase he used was “Prisoners of our own lust” or something along those lines.

PB: Yes, I mean I’ve read some of those things, I mean one did try and read them to understand. Because I think from my own perspective it was a matter of trying to understand, these weren’t the actions of someone who was just willfully trying to be at odds with the establishment. I think he genuinely held those views as an Africanist, as a believer in the African Union, African solutions and African dignity. I think he genuinely believed that he had a mission to challenge this.

AM: And they strike a chord if you read them. But what about, I mean, doesn’t somebody have to be really desperately egotistical to reject the whole of bio-medicine and scientific community, what’s that about. I mean, I can’t believe that he would be too stupid to distinguish between epidemiology and social determinants of health. He couldn’t have been that ignorant.

PB: Well I mean I think he was and is to some degree, has a lot of arrogance and pride as an individual. I think that is his personality, as a shrink speaking I suppose he has that personal style, that personality style. And it almost felt like once he had gone down that path, he couldn’t go back from it very easily without losing a lot of face.

And it would have been very undignified to backtrack having really nailed his colors to the mast. So I kind of feel like he painted himself into a corner, I genuinely believe he felt that.

And from a psychological level you could argue that, if you accept the premise of HIV being primarily sexually transmitted and you yourself are someone had and has currently a lot of partners, you know you don’t want to acknowledge that so you might want to find other explanations for this mystery illness that don’t challenge your own conducts and your own risk.

AM: That sounds like transference.



PB: Ja, I mean I do think that was an element of it, you know it's not the whole story by any manner of means.

AM: It's interesting to think that the psychological possibilities of Thabo Mbeki's. I never thought about it that way you know beyond sort of thinking he's an arrogant pig. I think we're just about out of time.

PB: So ja, maybe there's more, I must just think about it.

AM: Just to finish this session. Let's say there are some public health or medical students, students of psychology twenty, thirty, forty or fifty years from now if those still exist, and they're rummaging through the archives because they're wondering why a few million people were just wiped out of South Africa in the twenty first century. What would you tell those people?

PB: Well, I mean I think the terms genocide and TRC have been bandied about, and I can remember a long time ago, and it sounds a bit arrogant to say it now cause I don't believe I was the first person to say it, thinking I wonder if there's going to be a TRC around AIDS particularly around the Mbeki years, because we need a kind of a healing to understand what happened then. I think a historian might say that given Mbeki's place and time in South Africa's history, his ideas around Africanism and his resistance to the ideas of the West using Africa as a sort of medical playground and resisting Western constructions of African sexuality.

I think of the time, maybe there was sort of inevitability that someone like him would hold those viewpoints. Maybe that's a more generous interpretation, but his story would say well, you know he was reflecting the debates and issues of that period. I think a narrower, a different lens like a public health person might say, with justification, many, many people died through neglect, and the failure of the government to actually intervene in the face of the evidence.

AM: What did you just say, reflecting the debates of the period? I think when Hitler was reflecting the debates of his period he began exterminating Jews.

PB: Perhaps, you know you know, I mean.



AM: Is there an element of social engineering in Mbeki's, but there was...

PB: It was...

AM: I mean what's genocide; I mean how much intent is there in genocide?

PB: I mean there is irony in Africanists who believe in African lives and African people, and African futures being the cause of the deaths of many African people. So it wasn't, I don't believe, mal-intent, you know. He didn't wake up one morning and say, how can I ensure that many of my people, who are poor, largely poor and black who are dying will be exterminated. I mean I can't see that.

So it was tied up with his own personal political convictions, but you know in the time in the country's liberation perhaps you know he was, his thinking came out of those roots. You know, maybe I'm being overly generous in my interpretation trying to understand what, how did he, where did he come from you know he didn't just rise out of nothing.



AM: Ja, but here we are. But basically what the project is, fundamentally what it's going to be an historical archive of what I called "The Second Struggle". So what we're doing is identifying people who have seen being involved on the political side of health policy in particular HIV and AIDS in the last ten years, The Lost Decade, as *Dr Motsoaledi* called it at one stage. And just sort of collecting memories, I've kind off, it's not very structured, I'm not gonna ask you a lot of questions. But I'd like to do it kind of chronologically, so I'll intervene every now and then with a question or a kind of reminder or something. Basically it's a story telling essentially. Are you comfortable with that?

NS: Ja, I am.

AM: Good, I'm going to also record you on the Dictaphone. So Dr Simelela, thank you for joining us. Where would you liked to begin. Do you have a starting point?

NS: Ja, I have. I think the starting point is the time I actually got appointed as the director of the HIV /AIDS control program in the National department. I had been working in what was then Garankuwa Hospital Medunsa, as a lecturer in obstetrics and gynecology and as well as a clinician in that hospital, and had applied for this position after being encouraged to do so by colleagues in the National department.

So my first day, I started on World AIDS Day actually, in 1996, yes. And on that World AIDS Day, I travelled with the then Mister of Health, Anton Mazana, not Anton Mazana, *Nkosesana Zuma*, to three provinces. You know they were celebrating World AIDS Day and so we flew from one province to another in the helicopter. And she was very quiet, she didn't say much, she wasn't somebody who spoke a lot. And I was very scared, I was very anxious, I was not sure if I had taken the right decision about accepting this position. But I settled into the job and then you know the elections happened and the Minister moved into another portfolio and then the late minister Manto Tshabalala-Msimang took the position.



At that time I think the most pertinent and current issue was the prevention of mother to child transmission. That was the Uganda Trail had just come out and we started by organising a huge mission to Uganda to see what they had done, and to see what lessons we could bring. And I was optimistic, I was excited I thought, Wow, you know if there's something that can be given for mother to child let's jump on the bandwagon, let's do it. Its evidence based, we came back. And things were fine, really for the, for the first couple of months we were walking along the path that the international community was laying out and following the normative guidance. And then somewhere, something happened.

And I can only really in my mind remember the change happening with the emergence of the dissident dialogue, when the discourse came into play, the whole thing shifted, everything shifted overnight. The particular people that I didn't know them, we had read about those dissidence in papers and other books before but I didn't for one instance realise that they would be the source of so much challenge and controversy.

And obviously there were many other sources of challenges and controversy , you know the Durban 2000 conference, the whole thing about you know, does HIV cause AIDS, and then everything went from bad to worse. It was just incredible. So we moved into that storm, we were not ready for it, none of us had ever envisaged it was gonna come, and I kept going you know, from my own personal perspective because I actually was totally oblivious of the fact that anybody in leadership would believe things like, you know the issues that was being advanced by the dissidence you know, really I had absolute complete faith in the fact that, you know, science would prevail. That we would, you know be temporarily distracted and then, you know pick up and move. And day after day it became clearer and clearer that was not the route we were going to take, you know. We went deeper and deeper into this forest and into this storm. And a handful of us tried to keep the conversations based on evidence, but there was a lot of pushback.



And I can't say, you know I can't say that everybody in government was convinced of the fact that you know, garlic and lemons and whatever else, would cure HIV, I think there was something that I today can still not describe that paralyzed the rest of the leadership into moving and saying and pushing back on this.

So there were days and times when we had very interesting meetings, good meetings, where the people who were experts on the issue. So we believed, or at least I believed that we would come to a point where sanity would prevail if we allowed for these voices of the descendent groups to be given space in a way, just so that it became clear how stupid and foolish the whole argument was. And so convening the panel of experts and listening to the arguments, I mean that room was full of the best brains in the world on HIV, you know people who had discovered the virus worked with it, and who understood it back to front you know. And then there were other people who clearly you know had not found anywhere else in the world where they could speak or say anything about this unscientific claims they were making but were actually been given a very high level platform in South Africa. Saying the kinds of things they said you know and I believed you know here we've had an open transparent debate, here the voice of both international regional and national experts has prevailed and the chapter is closed, so you know when the dissidents get on the plane we pick up our problems and we move.

But that was not to be you know it just became more protected and became much more difficult now, being in the program, having to work with the issues, having to prepare documentation, having to be in meetings to actually keep pushing, you know.

But we kept working, we were implementing programs, and then out of the blue, you know when I was still in the program, well out of the blue in a sense that we hadn't, I hadn't anticipated that cabinet would come out with the next policy which was to provide anti-retrovirals to the survivors of sexual assault. And I thought. Ok, this is good. You know we're moving, we're pushing, and we are actually getting back into the space that allows us to get on top of this.



But everything we did came at a cost in a sense that you know, we had a court case that we had to defend, we spend hours and hours, and what affected me personally was being a gynaecologist, understanding the science and believing in the science and writing things that I really knew were really stupid, were not making sense, but because you know of the position I was in, of the portfolio I was holding you know, I couldn't step you know, out of that space and say, No I'm not going to do this. I was convinced personally that it was easier and better and at least it's my own personal style and strength to work from inside you know.

I didn't think that to perhaps walk out of my job and say well you know I'll be an activist for real and be on the streets was going to necessarily make my life as an individual better, you know. If I left my job I would want to go back to clinical practice, where I was confronted on a day by day by day basis with women who were not healing after caesareans you know, women who were very ill and I knew it was HIV infection and we had nothing to give them you know. So I felt it was going to be more frustrating to go back to that space, so I just kept my head down and just kept moving. There were many, many, many, many hours of work, many moments of absolute humiliation and abuse, you know. Where we, you just took it, you took the punch in the head on the face straight on. And you woke up the following day and you kept going you know, and for me personally you know. I did this because I had made that commitment to very special people in my life to keep fighting you know.

I've lost a lot of family members, I've lost a lot, I've lost a lot personally as an individual and I wasn't going to step, to take, you know a step back and say, no you know, it's well you know too difficult or it's to, you know I mean I had friends in the medical fraternity who felt that you know, we were not vocal enough, you know why aren't you refusing, why aren't you and perhaps you know in hindsight you know, when I see subsequently what happened not on HIV as an issue but the entire falling apart and rebuilding of our leadership, I only regretted why I hadn't been stronger in stating the issues you know, because I think, I'm brought up in a context of, a culture at least where you respect authority you do all these sorts of things and, not being you know a returned somebody who weren't gone into exile and who fully was imbedded and entrenched in the history of the struggle for this country.



I preferred to listen and take queue from those who had liberated this country so I thought well you know, let me keep going, let me keep going, and the point at which it became very clear that you know I couldn't carry on anymore was I'm in the fight for the treatment plan was fraught with days and nights of just hard work, pain, up down you know.

The good thing is that even within the people who were there you know some of the MEC's some of the heads of departments from the provinces were pushing, you know, KZN went ahead with their program, Gauteng went ahead with their program, Western Cape went ahead with their program. So I was comforted by the fact that even within the leadership there were differences and the people who could made decisions on behalf of their provinces were moving forward and doing that. And I was holding on to those people like, *Zweli Mkhize*, you know Deputy Minister of Health Gwen Ramokgopa who was really progressive in how she lead Gauteng, so I thought well if these people are around I have good company so to say. So when we rolled the plan, the first draft of the treatment plan, and it every time we got an opportunity to present it, it was cancelled. The meetings were cancelled, it just became harder and harder.

AM: This was the meetings that were cancelled by the minister?

NS: Yes, yes and the minister was cancelling the meetings and not giving us the opportunity to present this very critical document to parliament. A document we had been asked to produce with other members of other departments, treasury, department of health, provinces experts etc. And it cracked the foundation at the centre of it. It became impossible you know, but finally what then happened was because I think I started becoming more vocal in saying to the minister. I think we really, really need to push with the strategy, and so when she convened and established the task team, that was going to oversee the writing of the plan. She just side lined me as a head of the department.

They brought somebody in from the MRC who worked as the leader of the team. But I didn't mind, because it wasn't about me as an individual. The program was going to move, so we took the plan. That night we didn't sleep, we hadn't slept for nights. We wrote it, and we re-wrote it. And I remember one Saturday afternoon, I just got a call from the late minister and she



wanted everything changed in that plan. Including the proposals that we had made the costings that we had made.

Any reference to the people who had helped us, like the *Clinton Foundation* had to be removed and everything. And I couldn't understand the sudden change, because at every point when we finished a chapter, we presented it to her and other colleagues and everything was ok. And that's when I started suspecting that maybe this plan might never see the light of day.

We then flew to Cape Town and there was cabinet meeting convened, the then president was not in the country at that time, and the minister said; "No, you're not tabling this plan, you cannot table this plan in the absence of the president of the country." It was around midnight after we had finished of the last paragraphs in the plan. And I just thought no, it's not possible. That cabinet sit, that cabinet must approve this plan tomorrow. And fortunately you know there were people who really were on our side. There were ministers; there were senior policy people in the office of the president who just said. "No, it's going, it's going ahead. The president has given his go-ahead, even if he's not around, that the plan be tabled to cabinet, the plan be adopted and that this becomes a policy of the South African government. So come six in the morning, after we had walked up and down the passages the whole night and had been abused right, left and centre we finished the plan and then the time came to announce cabinet said. And because it had taken so long, people knew what was in the plan, the ministers most of them were happy with what was in the plan.

Treasury had done the budgets for it, so it was just a question of them looking at it and approving it, and the plan was approved. So in that joy and excitement post the approval, there was a press briefing and the minister was very unhappy, and she didn't even want to speak to me at that stage. I seized to exist in her eyes at that point which for me it was a victory, because look what we had been fighting for had been achieved. So the plan gets approved at the end of 2003 and then we entered a phase that for me was actually more difficult than the phase of writing the plan. That of now getting the drugs, getting the tender approved, getting the medicines flowing into the clinics. And December 2003 the plan is approved, we are into 2004 and it's January, it's February, it's March and there's nothing happening. The files are going up, you know, the pharmaceutical divisions meeting with the industry *Aspen* other people, but this



tender for procurement is going nowhere. And you know what I kept hearing was, you wanted a policy on treatment, you've got it so nobody must complain

So I said; "Minister but policy means getting the drugs in now it doesn't mean we've got a nice document on paper and it's on the shelf." And she said; "Well these tablets, you still haven't convinced me that they're not toxic etc." And I said; "Well that debate is over, the cabinet said it's done." And it was that conversation I think that broke my spirit completely, because it was clear that for as long as it was possible, and rational for the tender documents to be approved by her. The drugs were never going to arrive. And she didn't need a cabinet; she was just the only person there who could say yes or no.

AM: The tentacles of her obstruction were reaching everywhere.

NS: Yeah and you see the difficulty with what was happening was, when asked by the international community, we could only say. Yes we got a policy, so nobody could attack us. But its implementation was another story all together, and that's what happened. So it wasn't going home.

On one of the afternoons when I had knocked off, and faced the reality of my own family people in my own environment, who kept asking me; "When are these drugs arriving, you people have been saying you worked on these drugs and the cabinet has approved." And these are ordinary people, like I say when I speak about community I'm talking about my own family and my own cousins and everybody. And they were varying people, very educated people, people who contributed. Some of them teachers some of them nurses. My family is people who love education. And they were just dying, people were just dying and I didn't have a reason, I didn't have anything to say to them. We didn't have enough money to buy those drugs from the private sector for everybody who needed them even that small group of people who were part and partial of my extended family.

And I just, I think my soul just caved in. So I went to see the late minister and I said to her; "Look I'm going to resign from my job, I'm going to leave." And she said; "Oh why, why are you leaving? Your making progress isn't it what you wanted. You got now, you got the drugs so now you want to run away, because you know that what you've ask for is going to kill



people, so you don't want to be here when the toxicities come." And I said; "No minister that's not the case. The drugs haven't arrived, because you haven't signed the file that says the drugs should come. So I'm leaving because I'm tired of fighting. I'm tired of fighting against you or fighting against anything else that's standing in the way of me being able to go home and facing my family and saying, in the next two there will be drugs in the clinics. And you will get better." In fact, my words to her were; "I can't do this for you anymore, I can't lie on your behalf. I can't tell the country a story." Because you know the media were on us, when is the drugs coming, when is the tender going to be signed? I said; "I can't write this speech for you anymore on this issue because we're not going anywhere.

I can't do this for you, you know when my phone rings and I know it's you calling me, I don't have the energy to pick it up because I don't really know what I'm going to do or say to you. When I'm no longer useful for you, or for the country, I think the best thing is to move. Is to go because I don't want to be .seen as a barrier to progress. I'm happy that the policy has been signed. Now at least I can look back and feel that I didn't give up. But I don't have the energy to spend another," it was April, May I think when I resigned, another five months until the end of 2004 still saying the same thing. I said it's possible at the rate that we are going that it would take another year before we got the drugs in. And more and more people would have died, and I don't want to be around to see this.

So on that note I just left, I didn't have answers, I think I stayed shell shocked for a long, long time because it was bizarre, you know what was happening was really bizarre it was very, very strange. So I don't know who will answer the question, I know people have asked, people have written books, people have spoken to his excellence Mr Mbeki as to what he was thinking. I think a lot have people have tried to look for answers, everybody has come up with their own version of why and what they thought the government was thinking at that time. Those of us who were on the inside, sometimes you think you understand but to be honest with you, for me I think, I don't think I will be able to understand why people who fought so hard to make South Africa what it is or what it could be, couldn't see what was happening with HIV. And I think the impact of that is gonna take a long time to reverse. The same way as, I mean you call it *The Second Struggle* and the first struggle isn't over. The second struggle has yet to start.



AM: It's a continuation.

NS: Yes it's a continuation and I just hope that in addressing these struggles concurrently and intertwined as they are.

That we don't destroy ourselves as a people in South Africa. I've come back now after being in the UK, and I'm here now, and been in the AIDS Council, and it's toxic, you know, it's still very toxic it's just strange. And I'm trying and fighting very hard not to make it my own story, my issue. But it's amazing the HIV community and everything around this virus is toxic, it's toxic. Once people work in it, it does something to you. And it can either be really good, or it can just be something that is terrible. I just, I think it's right to capture this history because our children will maybe face a different challenge. But they should know, what happened with this.

AM: They'll be asking why half a million people died. And the point here is, I think not so much about accountability but about making sure that this is a part of popular memory that we have on tradition of popular memory in South Africa. And you know surely it would be a terrible break in tradition if we were to leave this out for future generations. But I get a sense from you that you're still reeling from the trail. So is that kind of what it feels like?

NS: Ja, ja it does, it does.

AM: The trail of you as a scientist, as a doctor or as a citizen?

NS: As a combination of many things. Firstly as a citizen of the country as a African woman, as somebody who's worked almost all her life in government, trying to push, making mistakes, going up, going down doing everything. Not perfect but as, ja, I think much more as a betrayal of what I stand for, and sometimes when I think back, having a loud fear, an unfounded fear to prevail sometimes. Because I could, even if I was the only one, I could have said, well I don't want to do this and leave and they'd find another director, there's no shortage of people. And sometimes I ask myself, why didn't I just do that? Because the memories you carry from having mean inside, they stay with you for a very long time. And I think they affect even the way you interact with what's happening now in a way, in a subtle way.



AM: You also came looking back at it through the lens of the present, I mean at the time when you were, when you say you were working from the inside. Did you have a sense of the scope of the problem or were you just seeing it as an epidemic.

NS: No actually it was, I saw it as a, for a few very profound couple of months. I really had to go into a space that is quite spiritual, because i kept asking.

What kind of God does this, what kind of God allows a country to liberate itself from something like what we had in this country, and then visits an epidemic like this on us. You know what kind of God would then, you know here now we're not talking about you know people being shot in the streets, or you know, rubber bullets and things. We're talking about little babies three, four, five months old, dying you know. Painful deaths you know, and adults dying protracted painful and undignified deaths, why?

Those things were playing in my head and I saw people, I'd lived with people who'd just disappeared in front of my eyes. From being 80 kg to being 24 kg and you're just carrying them like this. And these are brilliant human beings, people who had worked in the struggle and everything, and they were just dying, wasting away.

And we didn't care; the system at that point didn't care. We had discarded them as nonexistent, we had said whatever they had is a conspiracy theory, and if they were victims they were collateral damage and that's what bothered me. They just sort of became victims. It's like what we hear, there was a police shootout, they were chasing a gang of hijackers and somebody was passing by and they got caught by a bullet. That was our attitude to millions of South Africans. We were saying, oh well, this thing has happened but it's not really that bad, you could eat a few of these vegetables and you should be fine. Why is everybody making such a noise? And yet every weekend we were burying and burying and burying. And the statistics were there, you could see where the mortality was happening between 25 year olds and 42 year olds. And yet we were saying, no. We were in charge of the system, we were collecting the data.



AM: I'm trying to understand, because the way you talk about it, it's like they were martyrs in a just struggle. The way the system sort of treated those deaths, as if, you used the term collateral damage.

Do you think, i mean could the system have cared, was it possible at that point for the government for politicians to grasp the extent, the scope of the epidemic?

NS: Well I think no, and I understand that, I understand that in that time it probably wouldn't be possible. And then I say to myself, you had people who understood, who had grasped it, who were putting it in front of you and saying to you, here is it, and showing it to you.

There's a difference of being ignorant of something, totally not understanding its implications and therefore not acting because really you don't know anything, and your own people, your own scientists, your own community saying to you. People are dying, you've seen them. You go to their funerals, you bury them. And then you come back and you wear your policy hat and you say, no everything is actually quite fine. Because it's not as if there weren't people that were living with HIV that were known to all of us. Whether you wanted to believe or disbelieve, i mean if you take somebody to the doctor, and the doctor says well this is what's wrong with this person, this is what you need to do to make them well and to keep them alive. That's what we do.

But this time round we said; "No we need dissidents to come and convince us." We need this and this, the longer and longer we procrastinated the more and more people died. And then you know, the minister now, shows the statistics and, you know, we didn't have, there's very little we could hide behind at that stage. We had gone to Uganda, we saw, we came back. The same Nevarapine, we gave it to our people. Now what made it difficult to then make that jump from, mother to child, yes Nevarapine. Women who are survivors of sexual assault, yes therapy or whatever it is we wanted to do. People who's got HIV, yes you know, logically. That's why it didn't make sense. If we had put a total blanket approach that said; "We don't even want to see a single anti retro viral in this country." You know

It was these stupid reconstructed arguments that made it difficult. Where you could say, oh it's toxic. And we kept saying the science is evolving, you know, even now, even five years



from now we are going to be faced with toxicities, with challenges, and with side effects but people at least are alive. They have to take their medication, they have to manage it, and they have to. Like everybody else who has an illness, who has a cancer or whatever you know. So it's that, it's just how the conspiracy theories hijacked us. And we refused to stop, as South Africans and we are questioning community, we are a questioning country we debate things. But this time round we just got totally... I don't know what happened, you know, but now we're playing catch up and it's incredible. And I just hope that we now improve our understanding of this by seeing it as a socially, economically, culturally, behaviourally response. Not just you know, let's make sure that everybody gets the treatment that I think we will be able to do

But we then have to go inside ourselves as people as South Africans and bring the two historic fights together in a way and look at, because you know somebody said to me the other day, you know HIV is like any other, it's a virus you know, and it behaves like any organism, it wants to live. So it finds somewhere to live and it lives. But what it's doing is it's exposing how we treat each other, how we live. And if you turn it like that, you then stop fighting the HIV issue as, you know let's stop this virus from moving from person to person, and start looking at ourselves as people and how we treat each other in terms of our relationships, in terms of how we interact, in terms of how we support each other as communities.

And that is how you prepare, in a way that you prepare your own family if there's somebody who's got cancer, you do all the things, you prepare, you talk, you grieve, you counsel each other. Why is it different with this one, why do we then stigmatise and discriminate?

AM: Do you feel like there are still areas of the discussion we need to have as a society, are there areas we are not allowed to go, areas, no go places that are pockets of silence maybe, what do you think those are?

NS: I think the pockets of silence come from a number of areas.

Firstly you know this whole thing about multiple concurrent partnerships. Which we know drives the epidemic, we don't want to talk about these things, and we don't want to talk about how people establish sexual relationships. How nature makes it possible for you to just sit



in a room, look across the room, see somebody and say, oh I think I like that person, and in less than twenty four hours find yourself having sex with that person.

It's about us as human beings and how we express ourselves. People do that, even in this conference people are gonna be doing that. It's an AIDS conference but there's a human aspect of us. That's why there was a hallaballoo about testing in schools, because people want to believe you know, that young people mustn't know that adults are sexual beings, you know. We portray it as, oh it's gonna traumatise the children to know if they are positive, come on.

You know if I had a choice of knowing my status at fifteen and knowing I'm positive. That gives me a good chance to get into treatment, and have the choices other fifteen year olds would have in the future, you know what I'm saying?

But we moralised about it, we got into such a huff about it, we said oh the system will never carry this. The system is carrying everything, bad, good, mediocre whatever. There's a lot of things the systems in South Africa can't carry. We get bad service everywhere we go, you know. So why is it that we, everything in this society is not working, but South Africans are not sitting down and dialoguing about this rainbow nation, what are we gonna do about it, how are we actually gonna make it work.

There's a group of us on this side that's saying it's the responsibility of those ones who are leading, you know, and look at what they are doing, they are wasting. And then there's the disenfranchised you know, who sit and say well I am going to show my displeasure I am not going to go and vote. It's not gonna help. So there's still camps, you know, I blame you, I blame you, I do this. Somewhere along the line we are going to have to sit down and start a social movement on making South Africa work, really, really work as a country. And if we get to that point, on everything you know.

The education system is a mess, lots of people don't have jobs you know. But it's as if we want the cycle to just go on and on and on. And maybe it's in the way the system is laid out, leadership makes decisions about things, they prioritise here, there. I don't know how you actually make a democracy. A true, true, true one even with the differences we have, even with the different issues we have. I think we could work harder at coming together as South Africans



on issues than we are now. And I think the next challenge is going to be a social revolution. Really, it's just going to be about people who are going to be so angry about what they are unable to get as basics to live from day to day. And we can have a long theory behind you know, we struggled for so long. We can't do this, we can't do that. But I also find a culture of dependency.

AM: What about denial? Do you think that AIDS denial has a new incarnation now, I mean the victims of AIDS denial weakened and died. Denial has a new incarnation as something that paralyzes service delivery, you know, keeps people poor. Do you think that momentum is gonna build up. Is it still denial, is it still people turning their heads.

I mean when I travel in the rural areas and I see the poverty. I see areas that like Mozambique after they had seen seventeen years of civil war, I see heaps of rubbish and children barefoot and dogs, stray dogs. And I just think what is the reason for our country to look like Mozambique did after seventeen years of civil war. How did we get there? Sorry I'm taking over the interview, I just see it as a kind of conversation.

NS: I mean I, and this is what I think I'm struggling with right now. Is this what it is, is this life, and is this what we're meant to be doing. Just this recycling of things and whoever, if you're unlucky you are just there. And you know the levels of violence I think are an example of that. People are really willing to die, just so they can get something from your handbag because you look like you've got something. It's very serious, I really think it is.

And I think if, I'm talking from where I sit for instance, when I talk about messaging and communicating on HIV I'm saying, we're not being honest with the citizens of this country on what this epidemic is costing us. We keep celebrating every time there's an announcement of more billions to treatment. But we forget that if we actually seriously look at what the messaging is saying you know, don't have unprotected sex.

If we took that seriously on, and we cut down the rate of new infections. We'll have more money to pay the teachers, to pay the police. Because we won't spend all that money on health. So this is a dialogue communities must have, instead of demanding and then lapsing back into that very behaviour that is costing us in terms of health care.



And this is where the conversations are not going, because people are to scares. People are like, oh no government has promised, government said they are gonna do that, so you can't ask these questions. But we must ask people, that even in the context of liberation you must take responsibility for washing your face for crying out loud, clean your teeth for brush your teeth be a human being. Don't wait and wait, yes you maybe don't have a job or whatever, but stand up go look for one. If you don't find it, I don't know, I mean just, people say I've been looking for a job, I don't have a job or whatever. Ok if you don't have a job, what maybe I can't help you. But at least if you understand and hear this message. Don't then practice or engage in behaviour that will make you exposed, when you do then get a job, you're too sick at that stage, you know. There's a lot off, I don't know how we could have this intertwined dialogue on social issues and on HIV and on governance and how a country builds itself.

AM: Like Jacob Zuma's moral regeneration campaign, do you remember that it was some years ago, wasn't it around 1995.

NS: I think you know, we need something like that, we need to be prepared to confront what that would bring out in all of us, and say, ok if this is who we are how do we then collectively go forward, with our weaknesses with you know, and mitigate our own humanity in a sense. Because if we do that, then we capture the climate change things, we respect our environment; we do all those things in a subtle way. Maybe we're not doing it openly, but subtly, it's gonna come.

AM: You're talking about a dialogue as if it's something that needs to be orchestrated on a large scale, with public awareness and people sort of talking about things, The closest example I can think of is South Africa, that's come to that would have been the Truth and Reconciliation Commission. The act of open, very public, self-examination. We had victims and perpetrators anymore do w.

NS: I think there's a lot, there's a lot that is unsaid and unspoken and it erupts in strange places. And I think because we haven't reached a critical mass of these mini explosions, I call it, we just keep brushing it of you know, it just becomes a story. You know what they did, or somebody hijacked this one. But if you put all of those things together they create for you, for me at least, that is very concerning for this country.



AM: The small incidents are easy to sort of normalize.

SN: You need, it's almost as if you need an intelligence on that you know, instead of looking for arms, or weapons of mass destruction you should be out there, quietly getting this from the community, is an understanding what are the issues that are bubbling. Why did we get caught in this, how come we didn't anticipate and if we did, how come our response was so, oh well you know. It's this thing that I am worried about, you know even when we pick up the vibes, we can see it's building up. I mean this guy who just got shot by police, we all saw it and this man had nothing, but they descended on him, and they killed him. And it became a headline story for two, three days. Do you think much will happen? No it's gone away.

AM: What you're talking about is a, I mean we tend to look at policy and government responsibility. But what you're talking about is a social revolution that is sparked from the ground up. The need to understand the qualities of communities as supposed to the neglected areas of policy.

SN: On the back of which we must then build, as you find these stories you feed them back and we start answering peoples issues almost immediately you know, very responsive and say, ok this is what you're feeling, let's immediately work with you to get to a better place. So I think that's, there's that disjunction that, it's very much focused on, do we have this policy. No we don't have it so we fight to have this policy. The we get it, then we sit, we're not thinking beyond what happens after we've implemented this, if we don't reach where we need to reach, then how are we gonna move forward. So it's a lot of work, of thinking you know.

And I just, I'm interested to hear what young people are talking about these days other than, I'm interested because those are the leaders of tomorrow, those are the people who are best placed to rescue or at least to shape this country. And I know just from prior to the local elections, that they just feel disempowered they, they bribe their matric, they don't get jobs, they're very much disenfranchised.

AM: It's a very dangerous situation, if you look at revolutions across Africa inevitably there's a co-option and mobilization in the youth that goes on for, it's almost a precursor to conflict. We



have three minutes of tape left. Is there anything you would like to add, or any questions you would like to ask me?

NS: No, I think I'm keen to hear other people's experiences of it. I'm interested to speak to people who were on the periphery. Not very much inside, the locals and to ask, what it that you were watching is, what is it you think was happening in your eyes. And what would you have done if you were part of the groups, of us or whoever, who were in the middle and working. And maybe you think we didn't work hard enough, what were you thinking in your space as a South African as these things evolved and happened in front of your eyes. I'd love to listen to those stories because they might be helpful.

AM: Thank you so much.

NS: Oh you're welcome.

AM: That was really great.

