ORAL HISTORY PROJECT

Chronicles of The Lost Decade

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Interviewee: **Ruth Stark**

Interviewer:**Angela McIntyre**

Date of Interview:

Interview:

AM: Where is your beginning in the HIVstruggle?

RS: Well I personally worked with the World Health Organization for a number of years before coming to work for Catholic Relief Services in South Africa. So, umh, I was working in Papua New Guine at het time. Uh these where in the, uhm, lets see, I was in Papua New Guine in the 90's and that was whenthe epidemic started, so,uhm, so then I came to South Africa and, uh, was working with *Catholic Relief Services* here which is an international uhm NGO it's actually the official development and relief agency of the *United States Catholic Community*, so they work here in partnership with other ,uhm, organizations in this case our work was with the *Southern African Catholic Bishops Conference* uh.

AM: So this was in the 90s?

RS: Yeah that was the 90s. We came, I came to South Africa then in 2002.

AM: Okay in 2002. So to bring you back to 2002. That was, uhm, that was the high court (?) case.

RS: Yes sir that's right. That was what was going on.

AM: You arrived in South Africaaround that time.

RS: Around that time.

AM: And what was you impression?

RS: Uhm, well,uhm, ja mu impression was a country with great qualities a country that was being after liberation given a double blow of the HIVepidemic with suffering under that and not really able to respond really well not doing it but, what I found after being here for a while was that,uhm, the, the churches have been responding in the best way they could,uhm, and I think the history of all this happened goes back to the 1800's when,uhm, you know there were these communities came out andprovided,uh,you know needed services for people,uhm, in places I call, where no one knows and no one cares out in communities and uhm started hospitals and by the 1970's there where many hospitals maybe 50 hospitalsI don't know the exact numbers in, in what where the home lands at that time and then thegovernmenternment took those over for their

own reasons and the people started working more in primary care in the communities and picked up the slack there. So when,uhm, andthey where providing home base care and orphan care and,uhm and many, just whatever was needed, filling the gaps,uh, for health care and uhmpalliative care and social services. So,uhm, ja so then when treatment became available when people could save lives with Antiretroviral drugs there was this network out there that,uhm, that could, that was all ready to respond. I've gotten ahead of myself though, in this story.

AM: Maybe you've jumped a few years.

RS: Yeah. i jumped a few years.

AM: Okay lets go, lets go, to your your your first days, your firs days in South Africa trying to remember what what was, what did you encounter in your work situation what sorts of challenges?

RS: Yes,uhm, my, what I encountered were,uhm, many, what Iencountered were many ordinary people and communities were they were very, very, few services doing what they could for their neighbours out of their hearts, out of their faith, out of their ideology, political commitment whatever were doing helping their neighbours in little ways, people where dying, uh, children where being orphaned they would bring food, they would wash patients, try and transport them, doing what they could with no money. There were no recourses there for that,uhm, the uhm, meanwhile, so this was the day to day reality in many communities. We as a funding agency,uhm, helped as we could but in those communities people, you know, they didn't have computers, they couldn't write proposals, they didn't have electricity, there as no way that there could, you know, you know fit into the usual funding kinds of streams.

AM: Localised resources, there's the jargon…

RS: Yeah, meanwhile the *Catholic Church* had organised, had an Aids office because all these little hundred projects all over the place that, uhm, through the churches and the parishes trying to, to be of support as these cases were coming in I mean, people were sick, what do you do for them? And uhm so then they decided the needed to have some kind of a coordinating body so they could give that caregivers, uh, some training so that the quality of which ever service was

being offered out there would be improved and so they could look for resources so by, so that office had been established this AIDS office had been established in, in '99 and when *Catholic Relief Services* came, uh, was providing funding were able provide funding directly to the Aids office to fund these you know, these programs many of them, very little money, I mean a few thousand dollars here or there but, it made all the difference and,uhm, so that's how, that's how those programs started, then when PEPFAR(?) came you could keep, there where *Catholic Relief Services* applied for the PEPFAR grant in 2004, they received it for 9 countries,uhm, including South Africa and it was a grant for Antiretroviral treatment. And then those little places could not only do palliative care and take care of the dying but, they could keep people alive so that they could you know raise there children stay working.

AM: Tell me about those little places I mean you were, you went to clinics at the time were you practicing,

RS: No, no, no.

AM: But you must have gone to those places where no one knows –

RS: And no one cares yes.

AM: you must have visited those places can you just, just recollect for me, what did you see there in the communities, the feeling in the communities?

RS: It was interesting because in the early days, uh, of this program we where looking at it and we were thinking you know about the issue of stigma and we start offering these programs and people wouldn't come because they'd be worried about their you know neighbours knowing but I'm thinking of one place in just particular in Bronkhorstspruit the Sizananiarea,*St Joseph Care Centre*.

AM: Oh I've been to Sizanani.

RS: Have you been there?

AM: Yes.

RS: okay that's one.

Interview:

AM: I have beautiful things from Sizanani.

RS: Okay, yes, they do so it's a whole community and now they have orphan care and, and you know, they do everything now, when, when at that time we where, we where funding to do tests and so people would test and then they would bring their results and they would come and they would be evaluated for treatment so again worried you opened the door and start this and no one will come cause they would you know be concerned on the stigma thing. The day the door opened people were all over the place and people came they knew they, because,uhm, that centre like so many others had been in the community forever people knew and trusted those places it wasn't like going in and starting a project you know, I'm coming into a community and starting a project and we are going to provide treatment were gonna do this and that, they were there.

AM: And the relationship was there,

RS: And the relationship was there and they were part of the community, so you didn't have to do community mobilisation or all those kinds of things it was just there it was already there, so people came, it was all so interesting this and the people that we worked with uh, dare I say international consultants they gave us advice, uhm, were very concerned about,uhm, you know there had to be back doors where people come in, all these you know ways people could slip out after the treatment and but what we found in those centres where people just they all gathered together and talked to each other and supported each other and to me that spoke volumes about, yeah, what had been created over many many years in terms of trust and working together.

AM: You know I've always, uhm, said that about faith based organisations is that they don't, they face, they face different sorts of challenges then other organisations don't they? But that is really that is very interesting. So that was a safe place then for,

RS: That was a safe place and continues to be a safe place and, and so there are places like that all over and I, I think in terms of impressions some of these treatment sites as we call them in these communities are no more than freight container oh,uhm,that people come to or one of them I sort of an old station wagon, do you use that term, station wagon in South Africa, station?

AM: Yeah with the wood panels?

Interview:

RS: Yeah that old stuff and,uhm, with different,uhm, files in the back and you know, the nurse would go out and there will be a health worker in a shack and you know, a community health worker in a shack and,uhm, she'll have lined up the patients and she, the nurse, sees the patients and goes on the the next place so lots of efforts to keep things simple,uhm, use of funds not to do anything fancy, I always say nothing fancy just provide the best care that is possible to the most people, so, so, so you see, uh, also what you see is a lot of overworked people,uhm, the needs are great and the, the, uh, staff is always a little bit you know put upon I say.

AM: Uhm, you Say there where other places like Sizanani?

RS: Oh yeah.

AM: Can you tell me a little bit about them (?)

RS: Yeah, yeah, oh yeah, I think if you go to the, if you go up to the Rustenburg area you come to a place called Taplogo and Tapologo,uhm, how can I how can I describe it? It's many things, it started with the Bishop Dowling of,uhm, you know with the *Diesis of Rustenburg* very committed to,uhm, providing services for people living with HIVand on the Diesis property right next door to his house the built a hospice, the idea being that people you know, who where in shacks and very difficult circumstances could come and die with with people caring for them and in dignity but, ofcourse now, then treatment came and people could live and so there is a large,uhm, treatment program and that is where the nurse goes out to all these different sites and provides care. There is also freedom park. I don't know if you ever seen freedom park in that area and its, its communities around the mines and the old days where people, the mine workers were in hostels away from their families, women would gather around and different people would just gather around the,uhm, those mine areas and shacks and,uhm, they had no water, no electricity, no, no, services what so ever and,uhm, so, ah, the, at this site is, they've put up some freight containers and provide primary care there for people in those communities. So yeah, lots of so that's sort of the urban side and the rural and the more rural,uhm, I mean it's, I guess you can call it urban but anyways very densely, it's a very dense area of population moving to the rural areas where you have,uhm, you, you have farm workers and going out to the health workers going out to the farms to provide treatment for them and,uhm, and, uh, in some areas where the cases in,uhm, uh, the this aids offices manage to get funds to actually build some houses for

orphans that are living on their own it's very multi(?), uh, thing but another place to go would be the Winterveld where the *Sisters of Mercy* have been working have been there, I would, I would recommend you go,uhm, I was in South Africa in the 80's, I guess it was in the 80's and I don't know if you know the Winterveld area it was sort of a dumping ground in the old Apartheid days you know, people that didn't fit in to one population group or another or foreigners sort of ended up there it wasn't south African it wasn't Baputu Tswana it was that inbetween area, yeah very much a no mans land people just came and but from the different areas and countries there was no real sense of community in the sense you find in other places but it was a very, it's dry there is no water there's its it's the land its very difficult to grow anything on but the sisters of mercy started out there with the clinic and uhm, would in a freight container, these freight containers are wonderful everything starts in a freight container and then uhm, you know over the years they've built that place into, its an oasis, you drive through all the brush and the the uhm, shacks and the really desolate area and you come to this oasis where they've got bore holes and they've got uh they they so they can grow vegetable there with the water and the people who don't have grass and are very poor they give them a plot and they grow their vegetable on that and it's theirs. And they have a dental clinic uh uhm, they have nutritioncounselling they take care of TB patients they have an orphan program they you know its just what ever you need it is there and so its all so you know you walk through there and you ask what you see and I, I was just there recently and what I felt so good about are these lovely ground in the middle of of uh all this desolation and poverty they also have a school they teach people pass for matric they have adult education they have a sowing group they have all kinds of income generation they teach all these people to be welders and carpenters all that and uhm, and how people in community were so comfortable there that was what struck me the most you know ones walking through of groups of two and threeuhm, yeah I guesstheirs and really I had a good feeling about that.

AM:You mentioned the hospice in Rustenburg, you, you, you mentioned the treatment and when treatment when HIVtreatment became available things kind of change can you tell me about that transformation as a faith based organisation what did it, what did it mean for you that HIVwas no longer a death sentence it became a chronic, I mean that is the term we usually use,

Interview:

RS: A chronic illness. Well it certainty changed in terms of you know we had very many I mean Bishop Dowling can tell many heartrending stories of the children left behind and the children that were uhm, you know sick and now I mean for us I think it meant that uhm, you know people could raise raising their children was a huge thing and uhm, you know lives changed at this point there's one little boy uhm, and you know it is just the whole dynamic what we could do, as we worked with them and prayed with them uhm, you know walked sort of accompanied the on this sort of this journey or what ever of life uhm, there is one little boy who actually was the one who helped his parents take the Antiretrovirals you know and so that community thing ja, it was I don't know how to describe it very well and that's I mean we felt we have to do this I remember a debate at one time uhm, and maybe it was in all of our minds about what if the money forAntiretrovirals ends you know the church is not gonna have this money what do we do is it right to put people on when we don't know how long you know we can keep this up I mean who knows what the future holds, most days it looked pretty grim there was not in terms of uhm the public commitment to provide treatment and uhm the churches certainty don't have the money and were very great full for the PEPFAR money to to buy those drugs but I mean you could just tell uhm no external money is going to last forever for drugs that have to be given the rest of somebodies life not gonna happen you know is it ethical to you know start people when you don't know and I remember one church leader saying that you know if I can help someone have to more years of life to keep so their child is two more years old we have to do that. that was uhm that was the decision to move on.

AM: Uhm as a simple society organisation I mean there was for a long time uh uh uh tension between the department of heath and civil society (?) over HIVdenialism you know the obstructions of the you know rolling out the treatment program. how did you, tell me were you fit in as a faith based organisation to that.

RS: You know when when we asked for a grant we made an agreement we signed an agreement between US government us and SOUTH AFRICAgovernment at the time that we would follow government protocols we would use government you know we would do everything according to government protocols and we were happy to do that but the issue I think of working on the

ground was that uhm dear I say this in old days uhm for the church the government you know was the enemy so to speak and uhm so you just close yourself off and did what you could and hoped nobody interfered with the area you were working in and all that recalling that this is the church has been there for many years and gone through all the you know all the change so so now that that had to change and so the message was that we you know communicated was that uhm this is a new day we're here to support the government roll out of Antiretroviral drugs now the government had a strategic plan they a very good plan and uhm, their may have been all these barriers and conflicts and about it uhm, in government but it was their and our job was not to compete with government but we were here to support the government all out and uhm, to communicate that to our treatment sites and to government was are thing but I think we have always uhm, that uhm, you know in South Africain many countries health is is the work of the state is the responsibility of the state and uhm in our job as church with is primarily to fill gaps where those services where the state can't offer the or won't offer those services in certain communities and when government can take over then the church can move to other areas of work or geography you know and and look at those in other words uhm, with the exception of a few comprehensive primary care uhm, hospitals and tertiary care and primary care and centres and secondary level hospitals uhm, yeah most of that uh would be the roll of the government so it was really important that we work with government and we felt that they yeah we get to know government people and work with nurses and the nearby clinic if we could and uhm,

AM: Would you say experiences with that, with that were generally were generally positive collaborative?

RS: I think it depended on the place and uhm, but I think we got started on the right foot in that, in that every province that we as uhm, uh started treatment and every province we uhm, got the agreement of the provincial authorities so we could do that and so and we communicated with them as much as possible we shared uhm, are statistics and what we were doing with them anduhm, and so that has that over the years I mean it's been 9years now, over these years we've developed some very collaborative relationships and that's what we wanted and now as funding is decreasing we uhm, have different partnerships with government some of these places these outlined places uh were government's providing the drugs now uhm, for these clinics are, are

services are being connected to government services as a down referral or something else so, the intension was always to was to work together.

AM: on the political side of things, I mentioned this sort of, this sort of state of confrontation between civil society and government at this sort of higher levels, the levels of (?), national policy was, was your organisation, was the church ever sort of involved at that level?

RS: Yes, yes.

AM: Can you tell me?

RS: And the church certainly through various organisations uhm, the Aids office was represented uhm, on SANAC and religious as religious sector uhm, we had uhm, people from the treatment action campaign and working with us and some of this staff went to those meetings and uhm, yeah we also from the uhm, there is something called within the catholic church the Catholic ParliamentaryLiaison Office, and that is based in Cape Town I don't know if you've heard of it? but they that office does research and uhm, and advocacy with parliamentarians on different issues and certainly uhm,HIVwas one of those issues.

AM: Okay, advocacy with parliamentarians. so uh in the years when uhm, when the uhm,uhm, Minister uhm, under Minister MantoTshabalala'shealth ministry, I, I am interested to know about that the dynamic of that advocacy with parliamentarians.

RS: Yeah I mean the person that yeah could speak to them I think sister Alison would be the best to speak with and uhm, father Peter John uhm, Pierson who is the head of the parliamentary office in Cape town and I can give you his contact information some place yeah.

AM: Okay so you weren't particularly connected with them?

RS: No and again I mean if I work with an international organisation and uhm, have fairly strong views about uhm, that this should be done you know that advocass, advocacy is best done by you know our South African people we work with you know that uhm, you know it's just, yeah.

AM: Yeah. I think it's a position, it's a position that many south African doctors found themselves in as scientists and clinicians but also civil servants I they, they found themselves conflicted.

RS: I'm sure yeah I'm sure uhm, I'm sure they yeah, again not to go on the film here you can cut this out but uhm.

AM: This is off the record

RS: Off the record, yeah okay but I'm, I've just published a book called *How to work in someone else's country.*

AM: Oh I need a copy, I need a copy.

RS: It will be out in October but you can find it on amazon I, I just the publisher tells me nothing so somebody sent me the link it is on amazon telling you it is coming out and uhm, yeah *University of Washington Press*and it's very simple how to book on that and one of my don't does is uhm, get involved in the politics of another persons country ya know if I was working I mean as as a international aid worker,

AM: Are we still of the record?

CRS: Yeah, aren't we? I don't know we can decide show me what you show

AM: We can consult (?) I mean I'm very interested that the lessons you learned as a person you know working in someone else's county there are a lot of foreigners here involved in HIVfor a long time and I mean what you what you have to say about it is actually really relevant so tell me.

RS: Now uhm, yeah I mean wow how I did it was short it was I didn't have one reference so what it think and it had text boxes in the middle, there would be you know like something and then what to do and then text boxes what should be my journal notes and then uhm, I could send you it is on an email I could send it to you and then there's side bars on the side and those were from the other people other international workers that had a story to tell about how how things worked out for them in a certain situation so I mean it was very, like the first chapter was

uhm,relationship is everything and everyone is related and then I talk about the different relationships and then one of the second chapters is what to do if you get there and no one wants you uhm, you know it is that kind of a book so it is not any academic thing

AM: That's so interesting. Tell me,

RS: So but one of the things was uhm, you know its its really quite, I feel it is really quite arrogant to go into another country no matter how much you think you know about it and how much you think you've done for the people there and uhm, and be the face of advocacy what you, what you can do I help people that want to advocate uhm, you know sort of frame their discussion you know help them and that way but

AM: (?)

RS: Yeah that's it,

AM: That's really interesting and it think a lot of people face that dilemma that we feel passionate about things but, but I think you are absolutely right I agree with you in that. can you think of any sort of disaster stories? Think of an example you know foreign interference is just,

RS: I can but I just don't dare put that on tape ja I mean yeah in the early years I, I just, depends where this documentary is going. in the early years yeah, I think that we a lot of uhm international consultants that wanted you know wanted to tell you know to get in on the get on the band wagon and get in on the consultants fees and tell people you know, you know they had the answer of what to do and what we decided, this part you can record, we decided, you're my editor now, but what we decided early on wasthat uhm, we would use all, I mean, I'm, there is me I'm from the US and and there is one other person in our office that on this, on, in this activity we would work as a team with out South African counter parts and really work as a team uhm and you know make joint decisions and I didn't always like the decisions and you go with it anyway and uhm we would use all uhm South African all the South African experts all the experts we needed were here in South Africa and we would uhm and they would be out consultants and our experts and we did just fine. so uhm yeah we had really bad experiences in the beginning one of the things maybe I can tell this story, one of the things we had bad experiences with were all the computer people around the IT people the companies that wanted

to get in on the deal and they you know it was always of with the touch of a button you'll all the data you need to give to uhm you know the US government the South African government you know all the monitoring and evaluation and we made some in the early years yeah we bought into that and it was disastrous you know it took up the time with people you know uhm I think there were a lot of people also in the early days that wanted to use our sites as pilot you know we'll pilot so and so well our sites don't have a lot of money and they don't have a lot of staff and we're not really interested in doing any exotic new thing just taking care of patiants and you know to to have people involved with things it took a lot of time and you know and and theyre energy it was just yeah those kinds of things we had bad experiences with and we said never to do it again.

AM: well is suppose the presence of your organisation is an appealing place for people to come, isn't it, because your so long established and the relationships with the communities and so on, I think that's probably it

RS: Yeah. it's understandable, it's understandable but uhm I mean we have, I mean the priority has to be taking care of the people and the community and uhm there many interesting things to do but uhm you know if that if that takes away from saving lives then it's not worth it.

AM: I sense there are a lot more stories.

RS: there are and I wish I could tell me, I wish I could tell you.

AM: now I'm looking forward to reading your book. Now was intriguing because I used to work in Mozambique where of coarse at any given time forty percent of health expenditures are coming from donors so the phenomenon of foreigners telling people what to do came to such a situation that the department the minister of health finally said no you know we are going to have, we need some kind of a pooling arrangement were we can set the priorities you now the rest of you are sort of supporting the national agenda as suppose to everyone running around doing what they want, but I don't think it's quite gotten that bad in South Africa because were, were reasonably independent of foreign funding here up until you know until HIV.

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RS: Right, right well, I mean before HIV came along government, foreign government weren't putting money into South Africa because of you know, you know the political situation and all that it was only I think uhm well I wasn't here at the time so I don't know but I would assume that it was after 94 that things you know, that things you know that international aid became significant and then with the HIV it did uhm but uhm yes its been its been quite a, quite a journey.

AM: Tell me uhm, I just want to see (?), okay, I want to ask you a question that I've been asking everybody uhm since this is we're creating an archive here I want you to imagine that 20 or 30 or 40 years from now uhm let's say a medical student, a student of public health is digging through the archive trying to find some information of why a few million people just disappeared off the face of South Africa in the 21 century, what would you like to tell them?

RS: yes I, I'd like to tell them that probably one of the sad reasons that people disappeared uhm related how it's been forever you know people from first of all people from poor communities haven't received uhm you know good care form any from any of the government, the new government is trying but uhm there has been huge need so people with not just HIV but you know dying in child birth and dying of of uhm the usual childhood illnesses this is gone on for for years so with HIV uhm some how the idea even with the new government was uhm it, HIV was so associated with shame I think this is what I think you know and uhm that to say that uh you know people of colour were you know massively infected with this uhm sexually transmitted illness was to speak badly of them and speak badly of their culture and their behaviour and it think that was that was part of the great barrier uhm to pray the government stepping up and uh the need and providing the services. there's probably more to that story.

AM: I think there is a lot more to that story but I think we can yeah.