

UJ Sociology, Anthropology & Development Studies

W E D N E S D A Y
S E M I N A R

Hosted by the Department of Sociology and the
Department of Anthropology & Development Studies



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HIV and Disability

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- Programme and other information online at www.uj.ac.za/sociology -

Introduction:

I am Deaf, gay and was diagnosed HIV positive 13 years ago. I work at (GALA) Gay and Lesbian Memory in Action. My work at GALA focuses on HIV/AIDS outreach in the Deaf community, I have also been a role model for Deaf people living with HIV as I am currently the only Deaf person openly living with HIV in South Africa, I have publicly disclosed my status to my community, the Deaf community. I am aware that Deaf people in this country need support when they receive a positive result, when they go to a clinic or a hospital, I have personal experience of this, it was extremely depressing when I went for my HIV test. I walked into a clinic and saw an Sign Language alphabet poster, I thought they could sign but no one there could sign, no one could help me in my language. The doctor told me I was HIV positive by writing it down on a piece of paper. There was no pre or post counselling.

Role Models:

There are so many role models in the hearing community when it comes to HIV and AIDS, like Judge Edwin Cameron and Zackie Achmat, there are so many wonderful role models. I did not have any role model like Judge Edwin, I didn't even know about him, I didn't even know he was gay and Zackie, I always saw him campaign and he was all about some medication, but I never really knew what it was all about until the director of GALA, Ruth Morgan, told me that Judge Edwin Cameron was gay. And I thought "Wow, thank you Ruth for giving me that bit of information." He is such a wonderful role model. But in the Deaf communities there are no role models when it comes to these issues. I have had to take the decision to try and be that role model. At the time, I didn't even disclose and I knew I couldn't even tell my family that I was gay and HIV positive but one day I personally met Judge Edwin Cameron for the first time.

He celebrated his 20 years of being HIV positive. And I was absolutely amazed for the fact that somebody could live that long with being HIV positive and I thought let me come out to my community. We don't have a role model in our community let me be that person. I mean that was just my feeling, I thought well I have to come out to this community. I have to tell them they can also live that long. There are many hearing people that live that long even though they are positive and why should Deaf people not live that long.

So many deaf people have passed away because of HIV because they didn't know, they just didn't know and it all starts in the clinics. And that is the biggest problem, I know that's the problem, I know that in the clinics the majority of people patronize deaf people. They think "Ah shame, a deaf person'" and I am talking of personal experience. I will not let them patronize me, I am a normal... I am normal, I am human. I am just normal as you are and you know in my sign, I go there and I use my South African sign language to them.

I think that is the biggest problem. I did not know about the CD4 count, I didn't know about the viral load. I knew nothing. The director of GALA at the time, Ruth Morgan, gave me all the support I needed. You know she is just so wonderful and I love her for that, she has supported me, she just gave me tremendous support. After the tests, after getting the result that I am positive I was asked by her if I am on ARVs and that I need to know what my CD4 count is. She explained it all to me. I never knew until much later. And so I tried. She taught me all about the CD4 count; how it works, what the viral load is all about. She told me all of that. And while she told me everything Ruth interpreted everything for me and you know it was just so frightening,

to get all that information and then I went to go and get some more information. I went to the clinic gave a letter to the doctor saying I need to know my CD4 count because I didn't know. And so yes they stuck a needle in my arm and they tested it. I came back after a week and I was very weak. My CD4 count was not what it was supposed to be. I cried, I cried. It was shocking. And the doctor said don't worry I'll support you. And I was given some medication which I had to take different medication's vitamins.

I saw many Deaf people who were HIV positive, but they were not disclosing their status because some knew their status but could not talk about it because of the stigma of HIV. Deaf people got sick and have died without saying anything over the years, other deaf people believed that they had been bewitched by sangomas that why because they became sick and died. They did not believe they had a disease. Many Deaf people don't know about HIV/AIDS. They don't understand why the two words are used together. They only understand that HIV means that a person has a virus that will kill them. They understand that AIDS means that you are very sick and will die. They don't understand that its a sexually transmitted virus.

Some of the problems:

In my opinion the problem is the **lack of access to information about HIV/AIDS in the Deaf community**. There are many hearing organization in the HIV sector that give written information to the public, for example Soul City has books many comic and pamphlets and educational materials for Hearing community. Deaf youth and adults can't understand the written pamphlets, as the literacy level is too high.

These problems begin in the school system of Deaf learners:

- Not all hearing teachers at schools for the Deaf are fluent in South African Sign Language
- Sexual health and rights are not taught appropriately in Deaf schools, the subject matter is treated over sensitively by the teachers and no curriculum material exists for Deaf learners
- Not everyone knows how to sign the information, even if there is a hearing teacher or interpreter translating a speech at a school for Deaf learners, they don't have the difficult vocabulary in SASL for HIV/AIDS information accurately. For the speaker who is explaining STIs, and the interpreter used fingerspell (STI) but the learners don't understand what an STI is since there is not sign in SASL for difficult information
- For many years the focus in Deaf schools have been on learning how to speak (speech and hearing therapy) and therefore more time is placed on learners speaking and not on the curriculum
- South African Sign Language has been accepted as a medium of instruction, but many schools make use of bi-lingual teaching – they teach in Sign Language but hand over written material in English

These factors contribute to Deaf learners leaving school with low English literacy levels and limits their access to written information about HIV/AIDS.

Yet the health system providers and other service providers do not make the problem any better because:

- Booklets and HIV/AIDS information is printed in English

- There are no existing campaigns aimed at Deaf individuals, television especially. I have to say I am quite impressed with Soul City because they have subtitling, but they still don't always understand everything because of the terminology used and I am not the only one.
- There is not equality in the services provided to hearing and Deaf individuals such as pre and post counselling. I have gone through that experience. The clinic was not able to give me any information about a support group or other Deaf people with HIV/AIDS. I was the only deaf person at that stage, with a lot hearing people but then it all disappeared. And I know that a support group is very important for people who are HIV positive. But no, there is nothing for deaf people.

The result is that the typical health education programmes as a means of combating the spread of HIV/AIDS do not reach the deaf communities. That HIV/AIDS poses a serious problem is beginning to be recognised by deaf communities around the world, and some deaf associations have initiated small-scale HIV/AIDS education projects, where deaf people get basic information on the virus in sign language.

When deaf people go to have a test done to see if they are HIV positive or not they are patronized by the nurses in that clinic and Deaf people are not comfortable with being patronized at all. When these tests are conducted there are no South African Sign Language interpreting services available for them and the nurses in the clinic. There is no counselling done with deaf people when they come to do their tests. And they don't know what it means result to be HIV positive is good they don't know what it means result to be HIV negative is bad. And you know when you are given a result saying that you are HIV positive and these deaf people don't understand, they leave the clinic wondering, you know that. Then they know they are very excited of being positive because positive means it is a positive result is good. And there is no clarity, no clarity was given to them and the Deaf community has suffered for a very long time. The nurses, the doctor, they should all be able to communicate with Deaf people, but there was no access for me.

This is because people living with disabilities are assumed not to have a sexual life, and it's something that for us is of great concern because we're seeing an increasing number of people living with disabilities who are now at risk of contracting HIV and AIDS because they simply don't have the information or the access to that kind of information

These factors all contribute to a community that depends on themselves to access information through peer to peer conversations, and most of the time, the wrong information is spread. Resulting in high myths and misconceptions dominating the community and increasing the number of deaths.

The Deaf HIV/AIDS awareness project at GALA:

AIMS:

Currently the project aims to address the causes and effects of HIV in the general Deaf community in South Africa through the following activities:

1. Providing educational outreach on HIV/AIDS to the Deaf community through peer-education training, theatre, multimedia and other techniques.
2. Ensuring that resource materials and training materials are available to the HIV/AIDS, education and disability sectors to assist them in educational outreach to the Deaf community.
3. Advocacy that aims to deepen understanding in the health, human rights, and disability sectors of the prevalence and impact of HIV/AIDS on the Deaf community. Through participation in conferences, alliance building and solidarity with other social justice movements.

I will speak more broadly to some of our specific use of educational outreach through resource materials and participatory methods.

- At GALA we developed an educational comic for Deaf youth which is very visual and includes illustrations of people using (SASL) south Africa sign language. The comic written information. Called "Are your rights respected?".
I did work at a deaf school in Johannesburg and the learners understood the information. We developed the comic at GALA for Deaf people, so it was visual and dealt with basic information explaining HIV and sexually transmitted infections (STI), how they are transmitted, explaining rape and the use of condoms to prevent transmission. It also includes some sensitizing to and awareness raising of gay and lesbian issues and sexuality orientation.
- We did a pilot at Sizwile School for the Deaf of Soweto using two teachers assistants and two Deaf teachers. The Deaf assistants teachers also had lots of myths about HIV which we spent the majority of the time dispelling so as to give me accurate information about HIV. For example, one Deaf teacher believed that eating beetroot caused HIV/AIDS. She had gotten the wrong end of the story that the minister was encouraging HIV positive people eat beetroot in order to boost their immune system and stay health. They even believed that HIV was transmitted through kissing and sharing bath water or a glasses.
- I work with Cherae Halley (Hearing) on a separate project under the Deaf project called . **SEE IT!SIGN IT!KNOW IT!SHARE IT!** We do peer education training. The Deaf Peer Educators also experienced in their life difficulty in accessing HIV/AIDS information, we trained them in the correct information and then they share the information with their peers in the Deaf community.
- People need to receive information about HIV/AIDS in their own language, sign language. Materials on HIV/AIDS need to be easily accessible to deaf people. Formats that have shown promises include: different types of visual materials such as videos and theatre pieces as well as printed materials with little text. The digital stories manual and DVD pack is a tool for facilitating workshops in which Deaf people can easily access accurate information on HIV, sexuality and human rights.

The personal stories of eight Deaf peer educators captured on the DVD are used in conjunction with the manual to tackle a variety of topics, including educational and information barriers, HIV-related stigma, gender, sexuality, drug and alcohol abuse, and communication difficulties. This education should be designed to provide youth who are Deaf with accurate knowledge about safe sex practices and HIV/AIDS prevention.

- These trained peer educators then set up 7 Deaf peer education networks in their respective schools with a population of 993 Deaf students. These networks assisted in developing the "Deaf Peer's Education Theatre in Education project". We thank the many students and their head teachers for this collaboration and all their efforts St Vincents School, Sizwile school for the Deaf, Katlehong for the Deaf , Mc Khami School for the Deaf , organisation Deafsa and eDeaf in Gauteng. The Deaf peer educators also did outreach activities to 7 schools of the Deaf and Deaf adults' organization, and reached an additional 993 Deaf persons. The teachers and students responded to evaluation and they had a positive attitude. They appreciated the information for HIV/AIDS and sexuality. The deaf students understood the actors who signed clearly for the topics of HIV/AIDS and sexuality.