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The Silence Around Them: AIDS NGOs, Scaling Up and AIDS Fatigue in University Students

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**THE SILENCE AROUND THEM: AIDS NGOs,
SCALING UP AND AIDS FATIGUE IN UNIVERSITY
STUDENTS**

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Fall 2005

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Abstract

HIV/AIDS is undoubtedly one of the most talked about aspects of the political scene in South Africa. This epidemic is expected to ravage the South African population, wholly changing the country's demographic landscape. The most infected and affected generation is also the first generation to come of age in the democracy for which their parents fought. In this study, the author examines the attitudes and opinions of students within the aforementioned generation; current students at the Howard College Campus of the University of KwaZulu Natal in Durban. Largely, the students were found to be apathetic and overexposed to NGO's campaigns for awareness and activism around the epidemic. The study examines the phenomenon of AIDS fatigue, using it as an argument against the mandate for NGOs to "scale up" their programming and reach greater audiences.

Introduction:

In the September 8th issue of *Drum* Magazine, there are seven and a half pages of information about HIV/AIDS. The magazine, a pop culture weekly, catering to young, black women averages about 100 pages in length. On December 1st, the King's Park Soccer Stadium was full to capacity with activists, NGO workers and other allies for the 18th annual South African World AIDS Day rally. The most recent HSRC/Nelson Mandela survey on HIV-prevalence in South Africa, which according to some academics in the field is one of the most conservative estimates, finds that infection rates are still on the rise.¹ If KwaZulu Natal were a country, it would rival Botswana for the highest rates of HIV infection.

It is becoming ever clearer that the rhetoric around AIDS and the realities of the epidemic are two increasingly separate things. Historically, in AIDS initiatives, there was an assumption that if people were educated about the disease, it would be enough to change behaviors. The push for education and awareness campaigns in the late 1990s is a tribute to this hypothesis. With the maturing epidemic becoming the focal point of an ever growing number of NGOs and their public education programs while the numbers of those infected are still rising, it is clear that education is not enough. NGOs are now undertaking a variety of empowerment programs, condom distribution initiatives and lobbying projects.

The objective of this study is to examine the gap between AIDS NGOs, the messages they are sending and the audience(s) for their campaigns. It is set in the context

¹ Shisana O, Rehle T, Simbayi LC, Parker W, Zuma K, Bhana A, Connolly C, Jooste S, Pillay V et al. (2005) *South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005*. Cape Town: HSRC Press

of a conversation in academic circles surrounding the need to intensify and expand programs dealing with HIV/AIDS in order to address the growing numbers of people infected. I undertook a study of attitudes in university students, specifically looking at the University of KwaZulu Natal, Howard College Campus, in order to investigate this question. By looking at the political organs dealing with the epidemic and the political culture of the students, I wanted to investigate the impact of the current campaigns on these students. University aged people are the most heavily infected group in South Africa. In the age cohort of 20 – 29 year olds in KZN, nearly 1 in 3 people is HIV positive². In addition, these students are the first generation to come of age in the new, democratic South Africa. They were born in the 1980s, some of the Anti-Apartheid Struggle's most turbulent years. They are attending a prestigious university. They are, in many ways, poised to take over the country. Their situation is wholly unique in the history of South Africa. I wanted to understand what they were thinking about (what many activists call) the defining struggle of *their* generation.

Largely, I was shocked by the antipathy that the students felt about politics in general. Their reactions to discussions of HIV/AIDS and gender issues were less actively negative on the whole, but could still easily be classified as indifferent. Most simply expressed boredom with the topics; so called "AIDS Fatigue." The apathy of students surrounding issues of HIV/AIDS and gender equality, in the context of a vibrant NGO sector that is churning out awareness campaigns concerning the subjects and distributing thousands of condoms presents an interesting question in terms of what NGOs should be doing. Throughout the course of my study, I investigated the messages, programs and

² Department of Health Survey, 2003. The statistics in that report are based on extrapolations from antenatal clinic attendees' rates of infection. Strand, Per and Kondwani Chirambo. Cited in: HIV/AIDS and Democratic Governance in South Africa: Illustrating the Impact on Electoral Processes. 2005 Pg. 28

content of a handful of Durban and Howard College organizations that have programs that cater to university age students and deal with issues of HIV/AIDS and gender equality.

I worked specifically with contacts from the Gay and Lesbian Community and Health Centre, the HIV/AIDS Campus Support Unit, the UKZN branch of the Treatment Action Campaign, Agenda, the Centre for Civil Society and the Anthropology and Gender Studies Department of University of KwaZulu Natal. I also conducted two focus groups with students from the Gender Studies Department of UKZN and the Nelson R. Mandela School of Medicine at UKZN.

This paper is presented as a conversation of sorts between the activists, academics and students with whom I conducted interviews. The body of the paper is divided up into topical sections for the purpose of comparing the reactions of the different groups. The topics to be covered are getting the message across, politics and HIV, AIDS Fatigue and reactions to the government's past and present health policy. Through presenting these different perspectives, I am arguing that despite the myriad good works being done by NGO workers, a closer consideration of the audience of these campaigns is warranted in many cases. By taking time to reflect and consider the messages they are sending and the people that are supposed to be receiving them, it is my contention that the work being done by these organizations could be vastly more productive. This argument purposefully stands in contrast to arguments by such authors as Jocelyn DeJong³, who argues for a "scaling up" of current programs. I will use World AIDS Day as an example of the ineffectiveness of overextended campaigns. The concluding section of my paper will argue for a more localized and self-examining form of activism as a method of

³ See [Making an Impact in HIV and AIDS: NGO Experiences of Scaling Up](#).

combating AIDS fatigue and overexposure, especially in the face of the current government rhetoric around issues of HIV and AIDS.

Methodology

For this paper, I undertook a study of opinions and culture at the Howard College Campus of the University of KwaZulu Natal. This manifested itself in three different methodologies, focus studies, formal interviews and participant observation.

After spending time on the Howard College Campus over the course of the semester I began to understand the basic interactions of students in terms of spaces, times and groups. I then set about assembling focus groups. I used two contacts, Dee Naidoo, who I met through participation in the Gender Focus Study, and Thando Cele, who was the Bonela homestay sister of one of my peers, to help coordinate my focus groups. I conducted the focus groups using a tape recorder and a list of questions that was the same for both. However, the order of questions and the nature of follow-up or clarifying questions changed slightly depending on the course of the discussion.

I chose to work with focus groups with the students because of the nature of my project. Although I tried brief survey-type interviews, these were relatively unsuccessful as the presence of such strong rhetoric around HIV/AIDS prevented me from getting original and interesting answers. The focus studies worked well because they were designed as group discussions in which the participants could engage each other. Because of the sensitive nature of anything surrounding HIV, I thought it would be more useful to have a group discussion in which people could choose not to participate if they felt uncomfortable. The group discussion was also more conducive to asking fact-based

perception questions, where the group could hash out an answer, instead of putting the spotlight on one person to give, for example, a list of organizations in Durban dealing with AIDS.

To gain information from the NGO workers and academics I worked with, I conducted one-on-one formal, taped interviews. These interviews were based on two standard lists of questions (one for activists, one for academics) that were tailored to each interview and the organization with which the subject was affiliated. Interviews were most conducive to these subjects because the activists and academics busy. Having a flexible research methodology that was able to fit into empty spaces in their day was of paramount importance.

These two methodologies worked in concert to approximate the process of collecting a life history, in terms of getting a story from multiple sources to corroborate data. By getting a perspective from not only organizations, but also academics and university students I tried to form a more complete picture of the impact that NGOs were having on the population of Durban.

The participant observation section of my research consisted of attending events around town that dealt with AIDS issues, such as the Amnesty International Celebration of Women's Human Rights Defenders, the book signing of Khabzela: The Life and Times of a South African and the World AIDS Day Rally. In addition, I took notes on the popular culture references to HIV/AIDS, the various places where government issue condoms could be obtained, the conversations about AIDS around town and the public displays of red ribbons, ABC messages and other pieces of AIDS information.

Limitations of study

There are several limitations to this study. The first of which is structural; studying apathy is difficult. The students that agreed to be in my focus studies were, most likely more interested than the people who refused to be in the studies. Because of the nature of the findings, it was difficult to get a cross section of the political attitudes of the students.

Secondly, it was the end of term and many students were busy with exams, wrapping up the year, etc. This made focus groups hard to form and caused a good deal of absenteeism in my focus groups. It also meant that it was difficult to get a diverse focus study sample. I could only sample students in the departments where I had contacts, and the studies were mostly made up of their friends. A random sample was nearly impossible, as evidenced by many students' refusal to participate. I also could not find a contact for students in the political governing bodies of the school.

Thirdly, this study is by no means a comprehensive analysis of attitudes for university students in Durban. I only took samples of data from the Howard College campus of the University of KwaZulu Natal. This formerly white campus of the university is a prestigious university and the students are a very select group from the population at large.

Lastly, the organizations where I conducted interviews were only the ones I could get in contact with and who agreed to meet with me during this very busy time of year. Between the 16 Days of Activism Campaign and World AIDS Day, it was nearly impossible to get meetings scheduled with organizations around town, hence, my list of contacts is not as comprehensive as I would have liked it to be.

The Status of HIV/AIDS in South Africa

The AIDS epidemic in South Africa is overwhelming. Regardless of the survey methodology, the statistics given by reports on HIV prevalence on the Southern tip of Africa are horrific. A variety of social science fields from anthropology to gender studies to political science have joined the conversation on HIV/AIDS, contributing suggestions for mitigation, possible impacts and designs for social and political programming to cope with the epidemic. The epidemic, while starting out as a health crisis has been more and more frequently recognized as posing a danger to the social fabric, domestic security and development progress of some of the hardest hit regions in the world. Because of these macro-level implications, in addition to the various lobby groups and NGOs formed by infected/affected communities to lobby for treatment, legislation (to prevent discrimination against those who are HIV-positive) and government assisted support units, AIDS has become a deeply politicized issue.

The Mbeki Government and HIV – a Negative Response

In South Africa that politicization has taken a very particular course, especially with the Mbeki government. Mandela's successor has, historically, lent his ear to a group of so-called denialist scientists and thinkers; a small pool of "experts" denying the connections between HI-virus and AIDS. His appointment of Mantombazana Tshabalala-Msimang, a Leningrad qualified health professional and fellow ANC exile, as Minister of Health in 1999 cemented Mbeki's reputation as a supporter of the denialist school. Tshabalala-Msimang has gained the nickname "Dr. Garlic" from some of her

most generous critics and “Murderer” from some of her harshest.⁴ Her endorsement of healthy nutrition as a method of combating the virus, in addition to her ill-famed prescriptions of garlic, olive oil, beetroot and lemon have made international headlines. In the most recent celebration of World AIDS Day, the Minister of Health publicly refused to endorse ARVs as a method of treating HIV.⁵

The response from the executive, if not as direct has been no more helpful. The president now refuses to address HIV/AIDS, saying the issue has become too politicized. There is one widely circulated, anonymously written document which has been traced back to Mbeki or one of his close advisors labeling AIDS as a contrived disease that is: informed by deeply entrenched and centuries-old white racist beliefs and concepts about Africans and black people. At the same time as this thesis [that HIV is the cause of AIDS] is based on these racist beliefs and concepts, it makes a powerful contribution to the further entrenchment and popularisation of racism.⁶ Although these statements have never been accepted by Mbeki as his own words, in April 2000, he wrote a letter in which he “asserted the government’s right to question the very tenets of AIDS research and treatment...as well as to question whether anti-HIV drugs are too toxic to be of use in any situation in Africa, including prevention of maternal-fetal transmission.”⁷ Mbeki also continually stresses poverty alleviation as the primary method of fighting AIDS, which he labels as a disease which has its roots in poverty. This rhetoric, although based in truth, is insufficient. Alleviating poverty and many other social inequalities is undoubtedly important for long term change in AIDS prevalence

⁴ Kapp, Claire. “Mantombazana Tshabalala-Msimang: South Africa’s Controversial Health Minister.” *The Lancet* 365, 2005. www.thelancet.com

⁵ World AIDS Day Speech. 1 December 2005.

⁶ Anonymous (Mbeki). “Castro Hlongwane, Caravans, Cats, Geese, Foot & Mouth and Statistics: HIV/AIDS and the Struggle for the Humanisation of the African.”

⁷ Laurence, Jeffrey. “AIDS Lessons from South Africa.” *AIDS Patient Care and STDs*. 14(6) 2000. 289-292

rates, but it certainly must be accompanied by a comprehensive rollout of anti-retroviral drugs, support programs etc. in order to make the current state of the disease workable.

There are a variety of postulated reasons for Mbeki's stance on the issue. But whether it is a short sighted attempt to downplay the epidemic to make South Africa a more appealing investment for foreign money or because he believes that finding an African solution to the problems caused by HIV/AIDS is really the most helpful to his people, the results are the same. Between 700 and 800 people die in South Africa every day from HIV/AIDS, but the government still refuses a comprehensive rollout of antiretroviral therapies.⁸

NGOs – Education is not enough.

In the wake of all of the controversy over the government's official line on the epidemic, a vibrant NGO sector has sprung up. NGOs from the internationally acclaimed Treatment Action Campaign to rural cooperative HIV/AIDS and development initiatives have pressured the government to take a more active stance in the mitigation of the epidemic or attempted to fill in where the government has failed to act. The evolution of these organizations from awareness and education programs to more integrated approaches has followed the maturation of the epidemic. According to one author, "As the epidemic unfolded, many began to realise that awareness would not be enough to change sexual behavior. Yet in the early years there was optimism. Indeed, even today many AIDS programmes assert that with the right mix of information, skills training and

⁸ Kapp, Claire, 2005.

access to health services...countries can respond to the epidemic.”⁹ These information campaigns, however, seem to have been successful, in a 2002 survey by the Department for International Development the British agency acknowledged that awareness of HIV/AIDS was “nearly universal,” it was “not translating into behaviour change.”¹⁰ A 2004 survey of secondary school children in KZN found concrete evidence of this assertion. Nearly 80% of the students surveyed were able to answer the majority of fact questions about the transmission of Sexually Transmitted Infections (STIs) correctly.¹¹ Statistically, however, 417 of their 1113 student respondents were HIV positive. The failure of education to truly change the nature of the situation on the ground has led many NGOs to embrace the need for treatment plans, empowerment campaigns and other integrated responses. In addition, these efforts are seen to address root causes of the epidemic, like social inequalities.

Gender – discrimination, inequality and the epidemic.

One such category is gendered discrimination, which has been well documented as fueling and being fueled by the AIDS epidemic. Cases of extreme violence against women who “come out” as HIV positive, such as the case of Gugu Dlamini from KwaMashu who was killed after speaking about her status at a World AIDS Day rally in 1998, are increasingly common.¹² Violence against women is also a major factor in the

⁹ Msimang, Sisonke and Ekbaram, Sharon. “Moving beyond the Public: The challenge of Women’s Political Organizing in the Time of AIDS”

www.interfund.org.za/pdf/vol5_three/MovingBeyondthePublic-EkbaramandMsimang.pdf. Pg. 73

¹⁰ Jones, Peris S. When ‘development’ devastates: donor discourses, access to HIV/AIDS treatment in Africa and rethinking the landscape of development. *Third World Quarterly*. Vol. 25, No 2: 385-404.

¹¹ James, S., SP Reddy, M. Taylor and CC Jinabhai. “Young People, HIV/AIDS/STIs and Sexuality in South Africa: The Gap Between Awareness and Behavior.” *Acta Paediatr* 93:264-269, 2004. Pg. 266

¹² Albertyn, Catherine and Sireen Hassim. “The Boundaries of democracy: Gender, HIV/AIDS and culture”

spread of the disease, especially when it manifests itself in the form of rape and sexual violence. The injuries sustained in violent sexual encounters drastically increase the chance of HIV infection because of the bodily injury sustained in such encounters.¹³ Terrifying myths concerning sex with virginal women and cures for HIV/AIDS and perceptions of women enjoying rape are fueling sexual violence statistics that are among the highest in the world.¹⁴

Gender based discrimination unfortunately has also manifested itself in the activities of AIDS NGOs. It is most well documented, though possibly not most severe, in the Treatment Action Campaign. Discrimination ranging from lack of promotion within the organization to sidelining of women's issues to some cases of harassment and violence have been documented within the organization.¹⁵ In response to these issues, a number of gender and HIV based NGOs, like the Gender AIDS Forum have been formed, and are undertaking both internal transformation of the NGO sector and external empowerment programs which address issues of patriarchy, abuse and women's agency in negotiating terms of sexual contact.

Public Opinion – The Absence of an Outcry.

It would seem that such a thriving sector of civil society would be based on and emerging from a strong public demand for action on issues. HIV is ravaging the country and has been widely compared to the Black Plague in terms of the impact it has had and

¹³ Msimang and Ekambaram, in their article "Moving Beyond the Public" cite the recent gang rape of a young woman in Swaziland who was attacked because she was dressed in modern style clothing. The victim a teenage girl was attacked while waiting at a bus depot and raped repeatedly by the bus drivers. The authors go on to say that attacks like the ones profiled are hardly infrequent.

¹⁴ Leclerc-Madlala. Gender-based Violence Lecture. 3 November 2005.

¹⁵ Connor, Cha-Cha. "A Feminist Challenge: Women's Experiences in the Treatment Action Campaign in KwaZulu-Natal" Independent Study Project, School for International Training. June 2005

will have on the fabric of society.¹⁶ It would seem that an epidemic changing the very demographic landscape of entire regions of the world would inspire political outrage, movement formation and elicit some violent reactions from the people who are most affected.

Largely, however, this does not seem to be the case. According to an Afrobarometer report on public opinion and HIV/AIDS, “Southern Africans simply do not list HIV/AIDS as a political priority for their governments.” Indeed, the same report finds that in terms of political priorities, AIDS is listed 5th by respondents to open ended questioning.¹⁷ The authors of the report offer up a number of suggestions as to why AIDS, while ravaging the countries in which they conducted their surveys, would not register as a political priority. Whiteside et al present two theories as to why this might be the case, first that the subjects view AIDS as a private matter, to be dealt with in communities and within families. Because of the sensitive nature of the disease and the stigma attached to it, the authors postulate that there is little demand for public intervention because of the fact that people do not want to have their HIV status known in the general public. The other theory is that the subjects, faced with myriad other problems such as poverty and unemployment are engaging in “rational prioritization.” Because of the nature of the disease and the lengthy period between infection and symptom expression, the authors argue that AIDS simply is not the most pressing problem for many Southern Africans, the more immediate problems of adequate food and

¹⁶ See Garrett, Laurie. “Lessons of HIV/AIDS” *Foreign Affairs* 84(4): 2005 51-64.

¹⁷ Whiteside, Alan, Robert Mattes, Samantha Willan and Ryann Manning. “Examining HIV/AIDS in Southern Africa Through the Eyes of Ordinary Southern Africans.” Cape Town: Afrobarometer, 2002. Pg. 20

clean water will obviously take precedence over the problems of illness that is years away.¹⁸

UKZN – Children of the Struggle and the Generation of AIDS

Snapshot 1:

The University of KwaZulu Natal is home to the Centre for HIV/AIDS Networking (HIVAN), the Campus HIV/AIDS Support Unit, a student branch of the Treatment Action Campaign (TAC), DramAidE, multiple health clinics that offer Voluntary Counseling and Testing (VCT) free of charge, distribute between 40 and 50 thousand condoms per month while school is in session and provide a comprehensive rollout of antiretroviral therapies (ARVs) for five rand (this price, standard for all health clinic visits, is under negotiation and may soon be dropped for students seeking ARV therapy prescriptions).¹⁹ Durban is the site of the world's biggest AIDS awareness ribbon, 359 non-governmental organizations that deal with HIV/AIDS in some capacity²⁰, and was the host of the 18th annual commemoration of World AIDS Day.

Snapshot 2:

KwaZulu Natal has one of the highest rates of HIV infection anywhere in the world. According to a Department of Health Survey in 2003, 37.5% of the adult population in KZN was HIV positive.²¹ This unprecedented level of infection is

¹⁸ Ibid. Pg. 26

¹⁹ Stevens, Tanja. Interview. 17 November 2005.

²⁰ HIVAN Website. <http://www.hivan.org.za/aidsdatasearchAdvancedResult.asp>. Accessed 5 December 2005.

²¹ Adult is defined as a person between the ages of 15 and 49. The statistic is derived from Antenatal clinic data that extrapolates overall prevalence from infection rates of pregnant women attending public clinics. Strand, Per and Kondwani Chirambo. HIV/AIDS and Democratic Governance in South Africa. Pg. 27

projected to have impacts on every aspect of society, including national security and economic growth.²²

Snapshot 3:

AIDS Fatigue (AYDS fuh-TEEG) – *noun*. 1) A slang term for overexposure to HIV/AIDS public campaigns, information and discourse; burnout. 2) A general antipathy for dialogue about the epidemic; medical, social, economic and political. 3) A state of being (self-described as) informed, aware and sick of talking about it.

Collage

These three snapshots characterize what seems to be the reality of HIV/AIDS for young people attending Howard College. In my opening statements to potential subjects, I would emphasize that the interviews would not be about any personal aspects of the disease, merely the organizations and politics of the epidemic. This qualifier was purposefully placed in order to reduce the amount of rejections I got due to the sensitive nature of issues about the personal effects of the disease. I quickly learned, however, that ensuring my potential subjects were not uncomfortable with the potential sensitivity of the topic was not the number one concern. Many students I spoke to, both casually and in attempts to conduct interviews, were if not unwilling to participate (which some definitely were), at least unenthusiastic about what they saw as rehashing outmoded issues. Indeed, many of the students just saw politics as overdone. AIDS, they said, was just something they had talked about too much. The students were, overall, informed and aware, heavily affected and infected, and rather apathetic about the whole situation. The

²² See Arndt, Channing. “The Macro Implications of HIV/AIDS in South Africa: A Preliminary Assessment” paper presented at the International AIDS Economics Network’s Symposium on “The Economics of HIV/AIDS in Developing Countries.” And International Crisis Group. “HIV/AIDS as a Security Issue in Africa.” ICG Issues Report, No. 3. 2004.

students who did participate in the focus groups, despite their willingness to talk to me about the issues were only marginally more concerned about the issues.

The NGOs and organizations I worked with, on the other hand were largely very political, outspoken and antagonistic toward the government. Both sides of this discussion agreed that HIV/AIDS was a major issue; something that needed to be addressed. Both spoke about the need for an integrated response; education, treatment and empowerment. I don't believe, however, that the similarity of these responses is wholly because of the corresponding attitudes of the two groups. Indeed, the students in both focus groups seemed very able and ready to repeat back what they had been taught through NGO campaigns for their whole adult life. Their responses seemed to echo exactly the rhetoric of many education campaigns. When asked about gender, they came back with comments about rural women and prostitutes, when asked about the government's responses to the epidemic, they expressed mild dissatisfaction. The general questions, therefore produced less interesting findings as, it seemed to me, that students were repeating what they had heard in previous education campaigns. Upon more direct questioning, the student's responses were more original. Each section below represents one line of questioning I pursued during my focus groups and interviews.

Making an Impact – Getting their Attention

As stated before, there are at least 359 organizations in the greater Durban metropolitan area that deal with issues of HIV/AIDS on some level²³. Of these 359, the students I interviewed came up with three when asked them to name organizations they

²³ HIVAN Website

had heard of or with which they had interacted²⁴. They classified their interactions as very limited or non-existent. The one organization was identified as being “out there in the media” was LoveLIFE.²⁵

The messages of LoveLIFE have been widely criticized for being too abstract, too western and too flashy for the audiences they are trying to reach. Messages like “Born Free” and “Get Attitude” are emblazoned on t-shirts, billboards and other paraphernalia around the country.²⁶ These messages, however confused they are, do seem to be getting the attention of younger audiences. On a walking tour of a South Coast community with a LoveLIFE facilitator, she was widely recognized, and the children who saw her shouted the slogans back at her and were obviously very enthusiastic.²⁷ This impact, however, may only be surface level. The organization is still too young to have comprehensive studies of its effectiveness at reducing infection rates. Anecdotal evidence, however, does not paint a very positive picture. According to one focus group participant, “You will hear kids repeating the raps and things they hear on the adverts, but they don’t really understand what they are saying.”²⁸ Another participant stated her confusion about the messages LoveLIFE was trying to get across, especially with the images of burning flags or parties along with abstract slogans. She accused the organization of promoting an unachievable, Western lifestyle, and shrouding their messages so deeply in that image that many young people simply miss the point.²⁹

²⁴ The Organizations listed were LoveLIFE, the TAC and HIVAN, the later two having branches on the campus of Howard College. Focus Group, 18 November 2005

²⁵ Focus Group, 18 November 2005

²⁶ See Connor, Cha-Cha. “A Feminist Challenge: Women’s Experiences in the Treantnet Action Campaign in KwaZulu Natal.” Independent Study Project: School for International Training. Spring 2005.

²⁷ Chili, Sne. Interview. LoveLife facilitator. 18 September 2005.

²⁸ Focus Group, 30 November 2005

²⁹ Focus Group, 18 November 2005

Other organizations, however, completely failed to capture the students' attention. The only organizations other than LoveLIFE that the groups could list were groups that had branches on the campus of Howard College. The two focus groups answered differently when asked about how often they saw pieces of HIV/AIDS public information and awareness campaigns. The students of the Gender Studies Department agreed that they rarely saw those kinds of information, while the Medical Students admitted to seeing them often, but rarely, if ever paying attention.³⁰ The reasons given for their lack of interest were mostly because they saw themselves as informed, educated people and therefore no longer in need of such education campaigns. One student offered up the opinion that awareness and education campaigns were important because "...they do help people if you don't know about it...but once you do, I suppose they aren't really needed anymore."³¹

The problem with this conclusion is the fact that rates of infection are still exploding among university aged people, despite what some international development experts have called nearly universal knowledge of the technical particulars of HIV transmission and vulnerability.³² It is also tied in with the problems surrounding the difference between knowledge and behavior change. Even if there were 100% awareness, it would be difficult to make the argument that the rates of transmission would go down.³³

³⁰ My personal experience while living in Durban completely contradicts the finding of the Gender Studies Students. In the average day I see between five and ten mentions of AIDS in the average day while traveling through town. This discrepancy is, in large part, due to my heightened sensitivity to these pieces of information as a researcher studying the topic.

³¹ Focus Group, 30 November 2005

³² Jones, 2004.

³³ See S. James, et al. 2004, cited above for more information.

Politics and HIV – Apathy Compounded

Politics and HIV/AIDS have had a troubled relationship in South Africa. Just at the time when the epidemic was first emerging around the world, South Africa was in the middle of the anti-Apartheid Struggle's most turbulent years. When public education programs were emerging in schools to educate students about sexually transmitted infections and sexual responsibility, the schools in South Africa were called by the exiled political movements to become sites of resistance. By the mid-1990s, when the disease had begun to really take its toll on the first generation of infected people, the new ANC leaders were just figuring out the particulars of the transition from opposition movement to governing party. Indeed, even if the resources could be spared, "AIDS warnings and the message of safer sex were not subjects congenial to those savoring the euphoria of freedom."³⁴ Now that the disease has infected and affected the world for three generations, the Mbeki government is refusing to tackle the problem, either falling back on the denialist rhetoric of his Minister of Health or hiding behind talk of African solutions to African problems.

The AIDS epidemic in South Africa is so thoroughly politicized, and yet the young people of the country are so apathetic to issues of politics. Many of the students who refused my requests for interviews said they thought politics were over-done, boring or simply something they didn't want to talk about. Most groaned when I said I was a student of politics in the United States. Much of this political apathy is blamed on the demobilization of political will after the installation of the new government. Lebo Moletsane, a guest editor for *Agenda*, "Young people seem to think that the "struggle(s)"

³⁴ van der Vliet, Virginia. "South Africa Divided against AIDS: a Crisis of Leadership" *AIDS and South Africa: The Social Expressions of the Pandemic*. Palgrave Macmillan: Wellesley, 2004.

was their parents' responsibility and issue."³⁵ According to Nomhlanhla Mkize, director of the Gay and Lesbian Community and Health Centre in Durban for the people who visit her centre, "It's very much an "I don't care" attitude. I suppose it's just, "Well, since 1994, we're all free so what's the big idea?"³⁶

There was a consensus among focus group participants that, "...on campus they try to keep politics out of it to make it more approachable, at least for students, once there is some sort of alignment with politics then it becomes uninteresting."³⁷ The Chair of the UKZN branch of the Treatment Action Campaign, Claire, labeled the university as, "a strange place where people are apathetic and don't really care about anything," shortly after, she added that many students reacted badly to the antagonistic stance the national organization had taken to the national government.³⁸

Although it is true that HIV/AIDS is, at its core, a health issue, because of the macro level impacts it will undoubtedly have it is inherently a political problem. The provision of services and care for those who are infected is perceived, even by the students I interviewed, as a task for government. Participants in both focus groups suggested that it was the government's responsibility to provide for prevention and treatment efforts, especially with issues surrounding prevention of mother to child transmission. Suzanne Leclerc-Madlala agrees, saying, "...there should be some consensus on what should and needs to be done here and then we need that firm, decisive kind of leadership...[AIDS is] a political issue."³⁹ The students I talked to however, were not willing to take the government to task based on the fact that they were not

³⁵ Interview. 20 November 2005.

³⁶ Interview. 22 November 2005.

³⁷ Focus Group, 18 November 2005

³⁸ Interview. 22 November 2005.

³⁹ Leclerc-Madlala, Suzanne. Interview. 5 December 2005.

delivering the services that they saw as necessary. The gap between the students seeing that their government should be responsible and their unwillingness to hold it accountable for its inaction is noteworthy.

Denialism and Indifference

The students' apathy for the political aspects of the HIV/AIDS epidemic is also manifested in a general lack of information and confusion about what the government has done for the people. The responses of the students stand in stark contrast to the responses of the activists to whom I spoke, most of whom were very strongly in disagreement with the current policy trajectory. When I asked the question of what the subject(s) thought of the recent past government policy, both the activists and the students laughed, but with slightly different intents. The activists, on the whole, followed their laughter with a short statement about being utterly disappointed with what had happened, while the students' in the first focus group followed their laughter with seemingly guilty admissions of their lack of information on the subject. They admitted that they were confused about the current state of affairs but also dissatisfied with the denialist rhetoric of the president. They stated their disinterest in the whole debate because it was not only uninteresting, but they thought the conversation around the issues of nutrition, denialism and ARVs was unimportant.⁴⁰

The activists and academics, in stark contrast, leveled harsh criticisms against the government's slow and muddled response to the epidemic. Leclerc-Madlala:

They've pushed the problem aside and most of what they are doing now is too little too late and they add confusion to the whole mess...you get to the point where you would

⁴⁰ Focus Group, 18 November 2005

rather that these leaders don't say anything rather than speak up, and what a terrible thought that is.⁴¹ All of the activists and academics seemed to agree that strong political leadership on issues involving the epidemic had the potential to radically change the situation. If they did not need to invest resources in lobbying the government, they could invest more in programs that reached out to the infected and affected populations. Undoubtedly, this is the case. In addition, strong government leadership has proven effective in the fight against AIDS in a number of other cases, the most notable one occurring in Uganda where President Museveni instituted a comprehensive AIDS plan in the mid-1980s and "sustained political commitment at the highest levels..." and thereby successfully reduced the infection rate from nearly thirty percent in 1991 to around twelve percent around the year 2000.⁴² According to Amanda Alexander, a research fellow at the Centre for Civil Society at Howard College, the government is hiding behind affordability arguments, when, "The truth is that it has the money, it just doesn't have the political will. I think that is pretty pathetic."⁴³

AIDS Fatigue

The twin responses in the focus groups of seeing AIDS information everywhere and seeing it nowhere seems to point to a level of saturation in the Howard College population for information about AIDS. The problems of overexposure and AIDS Fatigue seem to be very real. According to one focus group participant (a medical student) she had been taught in school about AIDS at some length every year since she

⁴¹ Interview. 5 December 2005

⁴² Boone, Catherine and Jake Batsell. "Politics and AIDS in Africa: Research Agendas in Political Science and International Relations." *Africa Today* 48(2): 2001.

⁴³ Interview. 30 December 2005

was 13. The target audience for NGOs is growing ever younger, with LoveLIFE now targeting pre-pubescent children in an effort to stop high risk behavior before it starts. According to the organization's website, their target audience is children as young as twelve.⁴⁴ A medical student stated, "The problem with our age is that you don't really care. It is over done. By the time you get to varsity, you already know."⁴⁵

All of the activists I spoke to acknowledged the phenomenon of AIDS Fatigue. Claire, of the campus TAC stated, "People don't listen to AIDS messages anymore," noting that the strategies that the organization is adopting have become more aggressive and spontaneous. She cited grabbing the microphone at university functions and taking over the stage at other gatherings as some of the new tactics. The need to take people by surprise, she said, was very great.⁴⁶ A similar strategy was suggested by Suzanne Leclerc-Madlala of the UKZN Gender Studies Department, when she stressed the need for simple, clear and shocking messages in order to "wake people up."⁴⁷ The metaphor of waking people up was prevalent in a number of interviews I conducted. It seems as if all the activists I spoke with are aware of the potential that their subjects have for action and the fact that the apathy around issues of HIV/AIDS has the potential to be a temporary phenomenon.

Some activists employed more active language when talking about people's unwillingness to hear or talk about HIV. Claire, of the Campus TAC stated, "No, people

⁴⁴ www.lovelife.org.za/parents/index.html. Accessed 5 December 2005.

⁴⁵ Focus Group, 30 November 2005

⁴⁶ Interview. 22 November 2005

⁴⁷ Interview. 5 December 2005.

on campus don't want to talk about AIDS. They don't want to know, they don't want to talk about it..."⁴⁸

Amanda Alexander suggested that the problem is not with the audience, but the messages. She offered the opinion that,

...it just comes down to the fact that all these AIDS messages are trying to sell something that people automatically reject. It is not just like every other kind of awareness or prevention campaign, it is about something that people just do not want to think of in terms of being honest with themselves. It is just a really hard sell when you're doing a campaign.⁴⁹

Of course it would be difficult to address issues of long-term, chronic, latent illness contracted at such a young age. Disassociation is very easy. The students I talked with were very good at associating gender issues of the epidemic with prostitutes and rural women. Only after further questioning did they bring the issues back to the varsity. None of the students I interviewed fit either of the first two descriptors. According to Leclerc-Madlala, "It's frightening, that students who you think would be very aware, don't see themselves at particular risk for this disease. It's always someone else."⁵⁰

Overexposure, in conjunction with disassociation, does seem to be a primary reason why these students are so apathetic about the political issues of HIV and AIDS. Unlike the suggested reasons given in the Afrobarometer survey mentioned above, the students do not view AIDS as a problem to be dealt with in communities or families; they all expressed the view that the government should bear the burden. It is doubtful, as part of the rising middle class that these students would engage in what was labeled "rational prioritization" involving shorter term welfare issues, such as poverty alleviation.

⁴⁸ Interview. 22 November 2005

⁴⁹ Interview. 30 November 2005

⁵⁰ Interview. 5 December 2005.

Scaling up?

In the opening pages of her book, Making an Impact in HIV and AIDS: NGO Experiences of Scaling Up, Jocelyn DeJong states that scaling up may “indicate on the one hand reaching a greater number of people or, on the other hand, a notion of a particular size of population, activity or particular measure of interest.”⁵¹ In the face of growing infection rates in young, possibly uneducated populations, DeJong argues, in order to mitigate the socially detrimental effects of the disease. The argument is well fleshed out and very logical. What she seems to fail to take into account, however, is the audience of any of these programs. In the face of AIDS Fatigue, her argument seems to ring hollow. If the NGO sector doesn't have its audience's attention, then what good would it do to either intensify or broaden the scope of their efforts. In the former case it would only exacerbate the issues of AIDS fatigue, in the later, only reach more apathetic populations unless it moved into a context less crowded with NGOs.

In addition, to emphasize scaling up seems to assume that the present initiatives are on the right track. This is certainly not always the case. It is important to ask:

What are we scaling up? Failed initiatives? There are plenty of models around for what can be done, but how many of them are actually effective and really warrant a scaling up?

Maybe it's time to review these, do proper evaluations to find out do these [initiatives] make a difference and can they make a difference in a broader population?⁵²
The need for self critique and constant reappraisal of the impact, scope, intent and

efficacy of the programming around HIV and AIDS is a necessary component in the face of a changing and growing epidemic. Simply because these organizations are targeting young people, who are some of the most difficult audiences to captivate (due, in large

⁵¹ DeJong, Jocelyn. Making an Impact in HIV and AIDS: NGO Experiences of Scaling Up. ITDG Press: London, 2003

⁵² Leclerc-Madlala, Suzanne. Interview. 5 December 2005.

part to the ever changing youth culture in modern society)⁵³ they need to be flexible.

Amanda Alexander suggests that rather than scaling up, maybe NGOs should take a stance of “Let’s reflect or Let’s change our path radically if we need to.”⁵⁴

AIDS talk also needs to be less top-down. There is some natural dialogue about issues of testing and treatment among university women as reported in one of the focus groups.⁵⁵ Although not political in nature, it is something. According to Lebo Moletsane, “AIDS talk needs to be contextual, organic and specific. While experts are still needed to help communities develop interventions that work, it should be up to the communities to develop interventions that address issues relevant to their context.”⁵⁶ Part of that mandate is also looking at who is leading the current campaigns. The fact that the UKZN TAC branch is dominated by foreign students⁵⁷, the fact that much of the NGO organizing is done by individuals who are white, or male or both is a fact that needs addressing. To change peoples’ opinions and behaviors, it does little good to present leaders who have little in common with those they are seeking to lead. The promotion of community leaders in the struggle against HIV is of the utmost importance as a way of regaining credibility with the younger generations. The need for role models, especially black men to be clear with their status and their courses of action is tremendous. Empowering women through women’s organizations and really giving women, especially black women and rural women a voice in the face of this gendered epidemic is vital. Scaling up does not seem to leave room for this sort of home-grown discussion of issues or self-determination among communities. It does not leave room for changing who is

⁵³ Mkize, Nomhlanhla. Interview. 22 November 2005.

⁵⁴ Interview. 30 November 2005.

⁵⁵ Focus Group, 30 November 2005.

⁵⁶ Interview. 20 November 2005.

⁵⁷ Alexander, Amanda. Interview. 30 November 2005.

leading and who is following in the course of this epidemic. Despite the fact that the students I interviewed (and didn't interview) expressed apathy about issues of political organization, I do not think that filling the gap with NGO created dialogue is in the best interests of the students. As stated above, it would seem that this sort of imposition would only serve to further the cause of AIDS fatigue, overexposure and the accompanying apathy.

Scaling up the problems and the solutions

As alluded to above, scaling up the reactions to the epidemic also means scaling up the intra-organizational problems that are already present in the NGO sector. The present problems with sexism and racism within large organizations⁵⁸, and the lack of accessible role models would only be exacerbated by the increased scale be it through intensity of programming or broadening of impact. There is also no guarantee that scaling up would make the organizations any more accessible to their audience. The students have already reported that they have little or no contact with the organizations in town dealing with issues of HIV/AIDS. It is debatable how scaling up would effect this phenomenon, if it would require the organizations to cater to the students more, or merely to reach more students through present campaigns.

World AIDS Day and Scaling Up

December 1st was the 18th Annual World AIDS Day celebration. It was a worldwide event with rallies on all six inhabited continents, and in nearly every country that has a delegation in the United Nations. In Durban, the King's Park Soccer Stadium

⁵⁸ See Connor, Cha-Cha 2005

was full to capacity. Thousands of South African NGO workers, hospital workers, activists and academics descended on the stadium north of the city center. The keynote speaker, Mantombazana Tshabalala-Msimang, however, could not be heard. The muffled sound, in conjunction with the fact that she was delivering her speech, seated and inside of a three-walled tent across the field from the spectators made the content of her speech indiscernible. This glitch in sound amplification, however, seems an appropriate metaphor for the impact of the event.

Although World AIDS Day is a wonderful photo opportunity, the content of the day is often lacking. The unfortunate reality is “...every year we see, when World AIDS Day comes around, we see every year that it’s worse than the year before, that’s what we find out...that’s what it’s used for, to give us an update on how much worse things have become.”⁵⁹ Although this strategy might be good in terms of shock value, it does little to really “wake people” to the actions needed for successful AIDS interventions.

World AIDS Day is also not often a forum for new ideas or innovative happenings, “so you either wind up getting activists together talking to themselves...or the same old benefit concerts...”⁶⁰ Another activist offered the opinion that World AIDS Day was merely, “meant for Northern Countries to see pictures of orphans, people dying of AIDS, and remember “Somewhere, people are dying of AIDS, that’s so sad!” It is twice a year, just to remind them that something is happening. Here, it’s every day.”⁶¹ The students in the focus groups agreed, saying that they would possibly attend the rally, but more to see the concerts associated with the celebration than to hear the speakers.⁶²

⁵⁹ Leclerc-Madlala, Suzanne. Interview. 5 December 2005.

⁶⁰ Alexander, Amanda. Interview. 30 November 2005.

⁶¹ Claire. Interview. 22 November 2005.

⁶² Focus Group, 30 November 2005.

The problems that are present in the concept and execution of World AIDS Day seem to be consequences of the scale and repetition of the event. For 18 years the event has gone on, getting bigger every year, but not really effecting change or inspiring action. It seems as if scaling up, in the case of World AIDS Day has left this event somewhat hollow and without weight.

LoveLIFE and Scaling Down

LoveLIFE is another example of an organization lacking meaning, according to the focus study participants. It was the one organization, however, that the students named that caught their attention. The franchising practices and localized offices of LoveLIFE are based in hundreds of neighborhoods and communities in and around the urban centers of South Africa. By selling their brand name to already existing organizations, LoveLIFE has steadily increased its coverage of the country while using the facilities and resources already available within the community. The messages it is sending are, according to the focus group participants, inappropriate, but it had succeeded in getting people to listen. Maybe this example of scaling up, in terms of the organization casting a wider net was partially successful. By scaling up while decentralizing, LoveLIFE has pursued a unique strategy which seems to have worked. Would it be possible to take the scaling up strategies of LoveLIFE and combine them with more productive and clearer messages?

Denormalizing, Destigmatizing – You Need to Focus on the Audience

By ignoring the audience, the mandate to scale up efforts also misses the boat on a variety of methods of mobilization which would strengthen already existing organizations. By mobilizing people and gaining grassroots support for the missions of these organizations, the organizations would wield more power, both in terms of being more reliable mediators between government and the constituency but also because the wider support base would enrich and diversify the conversations within the organization.

As it stands, “No one sees it [the AIDS epidemic] as an item of discussion because it is so much a part of the background.”⁶³ The normalizing of the epidemic is a phenomenon that really must be reversed. Scaled-up, international efforts seem to have little impact except in the short term. However, in “Moving Beyond the Public: The challenge of Women’s Political Organising in the time of AIDS,” the authors argue that “...using that fear and outrage to inspire grassroots action...” could be an important step in the formation of a cohesive women’s movement against violence, poverty and by consequence, HIV/AIDS.⁶⁴ They cite the example of a Swazi woman who was publically brutalized at a bus depot for wearing modern-style clothing. When the police refused to prosecute the offenders, the women of the community took to the streets in support of the young girl. It the first demonstration of its kind in Swaziland, and although it was not wholly successful in achieving its aims, it did succeed in mobilizing the women around a common cause.

Mobilizing people requires a certain degree of emotional connection with the topic at hand. Denormalizing the AIDS epidemic, getting young people fired up about it,

⁶³ Focus Group, 18 November 2005

⁶⁴ Msimang and Ekbaram. “Moving beyond the Public: The challenge of Women’s Political Organizing in the Time of AIDS” www.interfund.org.za/pdf/vol5_three/MovingBeyondthePublic-EkbaramandMsimang.pdf. Pg. 73

convincing people that they should hold the government accountable for its inaction on the subject and building meaningful coalitions among the citizens and organizations that serve them is important, especially in the context of not only inaction on the part of the government, but deliberate confusion and ambiguity.

Urgency of the Response

Within the context of her argument about scaling up, DeJong makes the valid point that because of the alarming growth rates of the epidemic, a decisive strategy is needed quickly. Her solution is scaling up the responses of NGOs. Although I completely agree with this contention and assessment, I would argue that the solution is in drumming up support for NGOs already in existence. By reconnecting with their audiences, these organizations, rather than putting themselves in danger of compromising their messages through a process of overstretch, would strengthen and enrich their bases. Although changing people's minds is not the easiest route, I believe it is the most sustainable. Once organizations have the support that they need from underneath to lend legitimacy and strength to their campaigns, the option of expanding their reach will inevitably be left open. Simply scaling up seems to miss the point that in the context of HIV/AIDS, campaigns are aimed at changing behaviors, not simply achieving condom distribution quotas. Changing people's behaviors, as was shown above, involves more than education, more than distribution of condoms and more than making treatment available. It requires connecting with an audience. Those connections need to be made now.

Conclusion

The combination of denialism, activism and apathy that is present on the South African HIV/AIDS activism stage is an interesting mix of good and bad news. The good news is manifested in the 359 organizations dealing with AIDS in one city. The bad news is three fold; the government's denialism and problematic stances on HIV/AIDS issues don't show any signs of being rectified, infection rates are still on the rise and the young people, or at least many of them, are overexposed to AIDS talk and apathetic about politics. It is not surprising that the students I spoke to were tired of hearing about AIDS. They have been hearing so many different sides of the same story that it is difficult to imagine that the message could ever hope to come through clearly.

According to some theorists, like Jocelyn DeJong, the solution to the problem of rising infection rates is to scale up interventions by intensifying and/or broadening the scope of various organizations' messages. In the context of AIDS fatigue and government denialism, however, this response seems unwarranted misguided and wholly beside the point. What is needed is serious reflection on the part of the NGOs in order to understand the phenomenon of apathy, the reasons it is so prevalent and the importance of the audiences they are serving. What the NGOs need to understand is, if they want to effect change, then they must begin to listen to the silence they hear around them.

Recommendations for Further Study

There are any number of further studies that can be done on political culture and HIV/AIDS. It would be interesting to investigate the attitudes of students on other campuses, specifically those that do not have such a comprehensive AIDS treatment scheme. It would also be noteworthy to study the attitudes of young people who are not

as affluent or those outside of urban areas who are statistically more likely to be infected/affected by the disease. Because of the importance of the topic for the understanding of government's actions and the actions of the NGO sector, I think that surveys of political culture can be done on any segment of the South African population. These studies can be done repeatedly as well, because the ever-changing political landscape will undoubtedly have some effect on the opinions and attitudes of the people of South Africa. Also, there is some evidence that public opinion is beginning to shift in favor of making HIV/AIDS a governmental priority which, in the face of continued inaction by the ANC government could complicate their role as the de facto single party in South Africa.

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Appendix A

Interview Questions for Academics:

- 1) It seems to me as though the women's movement in South Africa is moving along very slowly while HIV/AIDS activism from an organizational level is trying to move very quickly. Both, however, seem to lack support among young (university age) people. Are the problems that these two movements are having parallel?
- 2) What are the intersections of women's issues and HIV/AIDS Activism?
- 3) Is a women's movement necessary in the campaign against HIV/AIDS?
- 4) Why do you think young people are so apathetic to issues surrounding HIV/AIDS? The women's movement?
- 5) What do you think of what the government has done so far with HIV/AIDS? The Women's Movement?
- 6) Do you think that HIV/AIDS NGOs in and around Durban are gender sensitive? How would you change or improve their programs around gender?
- 7) Do you think that talk about gendering HIV/AIDS has helped or hindered the dialogue about the issues?
- 8) How do you think organizations can overcome "AIDS Fatigue?" How should AIDS talk be reinvented?
- 9) What are your priorities for AIDS research efforts and money?

Appendix B

Interview Questions for Activists:

- 1) What do you think of what the government has done so far?
- 2) How effective do you think the condom distribution initiatives have been?
- 3) What are your priorities for money spent on AIDS prevention and treatment efforts?
- 4) How do you make the messages that you are sending to youth relevant?
- 5) What are the reactions of youth to politics?
- 6) Is it important to have political activism as part of your programming?
- 7) How gender sensitive are NGOs in Durban?
- 8) What do you do to work in cooperation with other NGOs around Durban? Do you think these cooperative efforts are useful?
- 9) What do you think of the mandate to “Scale up” your programming?
- 10) Do you think it is difficult to get youth to pay attention?

Appendix C

Focus Group Questions

- 1) How many pieces of HIV/AIDS public information do you see in the average week?
- 2) What role do you think politics plays in the epidemic?
- 3) What do you think of what the government has done so far?
- 4) What organizations can you name that deal with HIV in Durban?
- 5) How much contact do you have with these organizations?
- 6) How do you think gender plays into the epidemic?
- 7) How closely do you follow the political scene in South Africa?
- 8) How much do people talk about AIDS on campus?
- 9) What do you think of the condom distribution initiatives?