

# Mujeres Adelante

Daily newsletter on women's rights and HIV – Vienna 2010

## In Focus...

Kate Griffiths

## Vienna 2010 Declares: 'Rights Here, Right Now'?

**'Broken Promises Kill'** according to the t-shirts decorating scores of protesters who made their presence known early in the Opening Plenary of IAS Vienna 2010 Conference, the 18<sup>th</sup> annual global gathering of scientists, practitioners, advocates, activists, politicians, policy makers and people living with HIV. Bearing giant balloons and red umbrellas, the representatives of fundglobalaids.org had just staged a 'die in' in front of the conference venue, before addressing the opening session with chants of 'no retreat, fund AIDS!'

The refrain from the dais was much the same, whether delivered by unauthorised demonstrators or the diverse and sometimes divided panel of official speakers. The 'state of the epidemic' included gains over the last five years, but also a sense of betrayal at what

both grassroots activists and global health policymakers perceive as a 'backlash' against AIDS funding that has precipitated significant cuts in the global budget. This challenging new reality poses a potential threat to the emerging focus on human rights that is this year's conference theme.

### **Towards the Right to Health?**

Despite the sense of urgency amid increased austerity, the plenary provided an opportunity to reflect on the recent successes on the road toward 'universal access'. Most significantly, the last five years have seen Highly Active Antiretroviral Therapy (HAART) reach 5 million people living with HIV in middle-income and poor nations, including in South Africa where policy has shifted from neglect and denialism to increasing provision of life-saving HAART. Approximately 40% of those who need treatment now receive the lifesaving drugs.

Meanwhile, as population-level evidence of the prevention effectiveness of increased HAART access as a prevention strategy has

become available, the partial success of the IAS 2009 theme 'treatment as prevention' is also beginning to become apparent. According to studies conducted among sero-discordant couples in Southern Africa, HAART is up to 90% effective as a prevention strategy under such circumstances. As a result of these achievements, the epidemic may have 'peaked' in the early 2000's, though the absolute number of people living with HIV continues to rise, due both to new infections which continue at a rate of 7,400 per day and to the longer life-span of those with access to therapy.

### **Affording Rights, Catching 'Criminals'**

While these successes are notable, most of the plenary speakers focused on the distance between the realities of AIDS policy and decades old goals of a cure combined with 'universal access' and the threat to existing and future public health and human rights posed by shrinking budgets.

Rachel Arinil of Indonesia pointed to the gap between the impact of the

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epidemic on young people, claiming that despite representing 40% of new infections, they do not command 40% of global AIDS programming resources, and instead often face gross violations of human rights, including rape and trafficking. Dr. Sharon Lewin, of the University of Melbourne argued that increased access to treatment and longer lives for people living with HIV has increased rather than decreased the urgency of finding a cure for those infected and the need for research funding.

Paula Akugizibwe of the AIDS and Rights Alliance for Southern Africa (ARASA) more starkly posed the question of what it means to 'afford' the right to health and treatment not only by condemning the recent decision of G8 nations to pull out of funding commitments for HIV, but also by pointing out the spectacular spending and waste by Southern African nations and leaders on birthday parties, planes

...a potential threat to the emerging focus on human rights...

...the spectacular spending and waste by Southern African nations... while the commitments... to the epidemic remain unfulfilled...

and world class stadiums, while the commitments made in 2001 in Abuja to devoting 15% of national budgets to the epidemic remain unfulfilled. The costs for individual delegates to travel and attend the 2010 IAS conference itself, she noted, represent 20% of the funding allocated to fighting HIV and TB in Southern Africa.

Akugizibwe then delivered a comprehensive and impassioned overview of the intersection of human rights violations and HIV infections, pointing to the increased vulnerability to infection, criminalisation, violence and barriers to treatment faced by not only intravenous drug users, such as those described in the Vienna Declaration, but also LGBTI people, sex workers, prisoners, and particularly women. Human rights, in this view, are necessary, but not sufficient, to end the epidemic.

Concluding that 'we are making a decision to cut back on funds... [a decision] that will not just violate human rights, but which will turn out to be a foolish economic decision', Akugizibwe referred to those G8 policy makers responsible for cuts and often increased criminalisation of people living with HIV, asking rhetorically 'who, then, are the criminals?'

*Kate is a writer and ethnographer based in Durban, South Africa.*

## Criminalisation: A 'growing concern'

Kate Griffiths

Through years of advocacy and raising awareness on the impact, and especially the gendered impact of laws penalising transmission of HIV, criminalisation has become a 'growing concern', according to Richard Elliot, of the Canadian HIV/AIDS Legal Network. Along with Michaela Clayton of the AIDS and Rights Alliance for Southern Africa (ARASA), Elliot co-chaired a Sunday satellite session addressing the issue, emphasising the spread of legal penalties and prosecutions from Western Europe and North America to the rest of the globe, and particularly to African countries hit hardest by the epidemic.

The session, which included contributions from advocacy organisations in North America, Southern Africa, and Europe, helped to set the tone for this year's International AIDS Conference's special focus on the intersections between punitive legislation, HIV transmission and public health outcomes, as laid out in the 2010 Vienna Declaration's urgent call to halt the criminalisation of intravenous drug users, and to step-up research into the public health impacts of laws that impact people living with HIV.

Moono Nyambe, of GNP+, one of the organisations hosting the satellite, described the spread of both the global criminalisation of HIV transmission and the response; co-ordinated development of research, monitoring and advocacy. Over 600 people living with HIV have been convicted of 'crimes' in more than 80 countries for their role in HIV transmission or exposure. The United States had by far the largest number of prosecutions and the most severe penalties, with several European nations leading with the highest percentage of people living with HIV within the nation prosecuted under HIV-specific legislation. Meanwhile, Africa has recently seen the spread of 'model laws' that criminalise the exposure or transmission of HIV, including in Tanzania and Mozambique, along with documented prosecutions of two women in Zimbabwe.

### Impact

According to the experiences documented by health and human rights advocates, these laws tend to be 'selectively enforced' and have the greatest impact on marginalised groups, including LGBTQ people, low-income people and women. Such laws also, paradoxically, target those most likely to be aware of their HIV status, including women in countries where the epidemic is primarily heterosexually transmitted. Johanna Kehler of the AIDS Legal Network in South Africa argues that criminalisation of HIV exposure or transmission 'harms' women by discouraging treatment and testing, by increasing the risk of gender-based violence and abuse, and by limiting women's sexual and reproductive rights.

### Response

In response, policy and advocacy organisations, ranging from UNAIDS to the Terrence Higgins Trust, have begun to co-ordinate a response aimed at legal reform, education, engagement with law enforcement, emphasis on the most credible and recent scientific information about HIV and, most critically, developing a population-level evidence base that can confirm the negative public health consequences of criminalisation that advocates and people living with HIV have observed at the grassroots level in many countries. The challenge remains 'where to draw the line' when it comes to criminalisation, and how best to mitigate the impact of punitive laws, while simultaneously pressing for legal reform.

*Kate is a writer and ethnographer based in Durban, South Africa.*

## News from the Global Village...

### Rights Here, Right Now...?

Women-controlled prevention technologies are still unavailable or inaccessible to most women, and even the female condom – where available – still requires negotiation with sexual partners. At the same time, the reported early success of medical male circumcision trials, whilst reducing HIV transmission to men, may have repercussions for women if they wish to negotiate the use of male and female condoms to protect themselves; and people living with HIV continue to encounter high levels of stigma which can undermine treatment and positive prevention efforts.



Luisa Orza

What does this slogan mean for young women who face isolation, stigma and punitive treatment as a result of their HIV status or behaviours and lifestyles that could place them at higher risk of acquiring HIV.

What does this slogan mean for sex workers who face stigma, punitive treatment, and high risks of violence when they are not able to work within a legal framework as a result of their HIV status?

What does this slogan mean for women facing punitive laws in relation to vertical HIV transmission, often conflicting pressure from families, communities and health workers, abuse steamed by stigma and ignorance, and even institutionalised manipulation, coercion, and violence within the health sector?

## News from the 'margins'... Mmapaseka 'Steve' Letsike

### The need to move beyond...

**AIDS 2010 focuses on LGBTI, MSM, WSW and MARPs for discussions, presentations and debates. And although this might reflect a human rights-based approach to inclusive and comprehensive responses and services, we need to continuously question 'who' is represented and 'who' is representing in these events.**

We know that despite increasing evidence of the need for HIV and health-related interventions for same-sex practicing people, there are limited *formal* HIV prevention, testing, treatment, care and support

programmes targeting men who have sex with men, and even fewer for women who have sex with women. Interventions remain scares for many critical populations in many countries, and same-sex practicing Africans are one of them. Without immediate attention to this human rights and public health crisis, efforts to effectively respond to the AIDS pandemic in Africa may be seriously undermined and potentially reverse any gains made in the response to HIV and AIDS.

Persistent violations of human rights are exposing same-sex practicing people to increased risk to HIV and circumscribing their ability to protect themselves, their families and their partners. The denial of basic human rights as a result of sexual orientation may well be the most significant social risk factor for same-sex practicing Africans. Social vulnerability to HIV is not

an innate condition, but the result of legal, political and economic inequalities that lead to an inability of people to protect themselves from exposure to HIV, or to control its impact on their lives.

LGBTI, MSM, WSW and MARPs focused organisations are here in Vienna to draw attention to the lack of specific HIV programming and services; as well as the actions and inactions of governments, healthcare providers, and foreign donor contributions to HIV vulnerabilities, when same-sex practicing people face discrimination and unequal treatment in obtaining healthcare, safer-sex supplies, information or treatment. We need to move beyond these notable exceptions and begin to respond right here and right now!

*'Steve' is with OUT LGBT Well-Being, South Africa*

## Women's Realities...

Audrey Charamba

### A need for dedicated funds and resources

While the conference theme 'Rights Here, Right Now' is for the world to reflect on commitment to mitigating HIV and AIDS universally, women's rights activists have taken the opportunity to demand visibility of women-specific issues, by interrogating the levels of commitment by stakeholders to women's empowerment at this year's AIDS conference.

Speaking at the launch of the advocacy activities by **Women ARISE**, a new global coalition of women's networks, various speakers noted the need for commitment to provide adequate resources in order to create an enabling environment for achieving the reduction in HIV infections and in the burden of care, as well as the access to resources for women, as key in moving the conference theme forward.

Mabel Bianco, Director of FEIM and co-founder of Women Arise, urged participants to debate and interrogate honestly issues of resource allocations in relation to the realisation of women's rights.

*Women need special access to services; they need to begin realising their right to live their lives free of violence and discrimination...and how is it possible to have these services without money?*

Dr Nafis Sadik, UN Special Envoy for HIV and AIDS in Asia and the Pacific, argued that there was a huge information gap in most sexual and reproductive health and rights programmes for young women and girls, as most programmes targeted only married women. She further stated that there was need to empower young women and girls, through relevant and appropriate information dissemination, to enable them to begin utilising and enjoying their sexual rights from an informed perspective. According to Dr Sadik:

*Traditional and cultural norms across the world were not*

*designed to protect women. Young women and girls in particular are vulnerable to unwanted pregnancies and sexually transmitted infections, including HIV infection. There is need for women's organisations and civil society organisations to lead in advocacy for access to information as a way of empowering young women and girls.*

She also underscored the need for political leaders to begin acknowledging that primary healthcare for women was not charity, but a policy and rights issue, that contributed directly to the mitigation of HIV and AIDS.

*HIV and AIDS know no borders; similarly advocacy should be international and must deliberately cater for girls. Ignorance about sex and sexuality, which is the norm in most societies, coupled with poverty, increases girls' vulnerability to infection.*

Dr Sadik advocated for a three-pronged campaign, which focuses on education, gender equality and women's sexual and reproductive health and rights as one way of ensuring that women's issues are addressed in mitigating HIV and AIDS.

Using the participatory approach, Meena Seshu, Executive Director of SANGRAM, and Zonibel Woods, of the Global HIV Initiative, continued the discussion and urged participants to share their visions and expectations from the conference.

Most participants cited the need for donors to commit to allocating a certain percentage of funding to women-specific issues, while others urged that governments must put in place legal frameworks to ensure that women were not side-lined in the HIV and AIDS discourse and interventions at a country level.

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*I think that by the end of this conference we should see the establishment of an information-sharing centre with help lines to point women to assistance and appropriate networks in terms of HIV interventions. Information is power and as women we can never have enough of it – said Katja Fierkat of the Health Protection Research Organisation based in UK.*

Another participant urged the conference to launch a campaign for access to the female condom worldwide as a way of empowering women.

*We need empowerment in the form of access to female condoms, and the knowledge that we can contribute to processes even as HIV positive women, not just await prescriptions from all-knowing donors and programmers.*

World YWCA Secretary General, Nyaradzayi Gumbonzvanda, argued that it was insufficient to sing the theme 'Rights here, right now', without interrogating access to funds, and urged the Global Fund to consider increasing budgets for interventions specifically targeting women.

Global Fund Director for External Relations and Partnerships responded that his organisation had committed to funding women and girls, through the Gender Equality Strategy and Sexual Orientation and Gender Identities Strategy. He also encouraged women to begin to include other issues affecting them in their proposals, such as gender-based violence and maternal mortality, in addition to HIV and AIDS.

*Audrey is a media  
and communications  
consultant from Zimbabwe*

## Women's Voices...

Sabrah Møller

# Generations and unifying issues?

**The session entitled 'An inter-generational conversation: Does the struggle for realizing the human rights of women still matter to young women', took place on July 18 2010. It consisted of a panel of five women representing selected age groups. The women were in their 20s, 30s, 40s, and 80s, thus representing both 'women' and 'younger women', all working within the HIV movement.**



One of the panellists emphasised that the struggle between the older and younger generations were alike, only with different issues. While young women today struggle with HIV and AIDS, protection, care, safety, and freedom of violence, they could still use the experiences of the older generation, who already has 'fought their fight'. The apparent gap between the two generations highlighted in this comment, was also underlined by Dr. Saadiq responding that the power relations between younger and older women should be broken down, as there might be a gap between the two generations; also mirrored in the different expectations of life, including sexual rights. She concluded by asking if the women who fought for these rights would allow their daughters to enjoy the same rights as they had in terms of

sexual health, questioning whether or not these rights have been internalised.

Oriana, a third panellist, concluded that young people are not 'helpless', and that women and younger women should not be seen as two generations, but 'just as women'. In addition, Oriana also illuminated that power relations should be shared vertically, as opposed to horizontally, which, in her view, has not been the case thus far. The session ended in recognising that although culture, tradition, religion, as well as stigma complicate intergenerational dialogue, women should focus more on the unifying issues and not as much on the generational and other divides.

**Sabrah is with the AIDS Legal Network, South Africa**

## UPCOMING EVENTS

### Tuesday, 20 July

08:30–09:30 *Gender, Sexualities and HIV/AIDS in Latin America* Women's Networking Zone

09:00–10:30 *Plenary Session* Session Room 1

9:30–10:45 *HIV and Injection Drug Use: Making Harm Reduction Work for Women* Women's Networking Zone

11:00–12:30 *Social Sciences and Interventions: Putting Theories into Practice* Session Room 9

13:00–14:00 *Update on Microbicides* Session Room 7

13:00–14:30 *Women IDUs: Why so Many Barriers When There are so Many Needs?* GV Session Room 2

13:45–15:00 *Women Living with HIV in Europe and Central Asia: Launching a New Network* Women's Networking Zone

14:30–18:00 *Safer Feeding for HIV-Exposed Children: How to Integrate Infant Feeding Into Community-Based HIV Prevention Activities* Mini Room 10

18:30–20:30 *Sex Work Legislation: Solution or Problem?* Mini Room 2

Naina Khanna, Waheedah Shabazz-El

# Special report:

## HIV Prevention Justice: Not Optional for Women

**The HIV epidemic among women in the United States is not driven by women making 'risky or rash decisions'. Until we redefine vulnerability, and transform the social and economic context in which women live, play, work, and love, we will fail to achieve prevention justice for women and HIV will continue to ravage our sisters, daughters, mothers, and grandmothers.**

Women comprise nearly one-third of HIV infections in the U.S. today. Women of colour, especially Black and Latina women, are disproportionately impacted by the HIV epidemic – representing over 80% of infections among women. AIDS remains the leading cause of death among African-American women between the ages 25 to 34 years – women in their prime as productive and central members of our communities. And data recently released by the U.S. Centers for Disease Control and Prevention (CDC) show that adolescent girls bear an undue burden of common sexually transmitted diseases among the youth.

With this kind of data at our fingertips, federal agencies responsible for the health and well-being of Americans ought to have a sense of real urgency; and make this critical epidemic among women and communities of colour an immediate priority.

Yet, even the CDC – the federal agency responsible for coordinating

public health prevention efforts – prioritised the release of data on STD rates among men who have sex with men (MSM) on National Women and Girls HIV/AIDS Awareness Day on March 10, 2010. While these data are vital for addressing the urgent prevention needs of gay and bisexual men and other MSM, the poor timing of the release may lead some to question the CDC's own awareness of the impact of HIV on women and girls.

Until we commit to systemically addressing the deeper structural issues that place women, gay and bisexual men, and communities of colour overall at disproportionate risk for HIV, we will fail to achieve HIV prevention justice.

One such structural issue is the current risk assessment system that perpetuates misperceptions in the community about who is truly at risk for acquiring HIV – resulting in late diagnoses and unnecessarily poor health outcomes for women with HIV. HIV prevention efforts to date have been largely focused on changing the decision-making and risk-taking behaviour of individuals. Yet, a majority of women testing positive for HIV in the U.S. does not fit the narrowly defined high-risk categories for HIV transmission, which are entirely predicated on individual behaviour and personal knowledge of exposure to risk (for women read: 'high-risk' heterosexual contact or injection drug use). 'High-risk heterosexual contact' is defined by the CDC as

*'heterosexual contact with a person known to have, or to be at high risk for, HIV infection'.*

**...a majority of women testing positive for HIV in the U.S. does not fit the narrowly defined high-risk categories for HIV transmission...**

Most of us would agree that a system built upon people seeking, or being offered HIV testing due to knowledge of the complete sexual and drug use history of their partner is doomed to failure with deadly consequences. Yet this orientation has driven surveillance efforts and resource allocation towards HIV prevention efforts.

Reimbursement rates for HIV testing vary widely, and are dictated by data collection about behavioural risk factors. Since we do not accurately capture and disseminate data about what puts women at risk for acquiring HIV, reimbursement rates for testing non-injection-drug-using women are artificially deflated. Consequently women are often discouraged from (or outright denied) an HIV test, despite the World Health Organization's revised guidelines to encourage earlier treatment of HIV to promote better health outcomes for HIV-positive individuals.

Case after case of women being turned away from HIV testing have been documented by the National Women and AIDS Collective (NWAC); and a recent report released by the National Alliance of State and Territorial AIDS Directors (NASTAD) supported these findings, with testing service providers admitting that contract restrictions and reimbursement rates drive their testing and outreach efforts.

Providers are contracted and paid to test populations perceived to be at highest risk for HIV transmission. However, women's vulnerability to HIV correlates more accurately to our risk for acquisition. Risk for acquisition is a very different picture – coloured only partially by personal behaviour and more by our social and sexual networks, gender inequity, power dynamics in relationship, socio-economic status, community and family infrastructure, and accessibility of healthcare and accurate health information.

Organisations with a track record of working with women living with, and vulnerable to, HIV infection have developed their own approaches to address the complex structural issues impacting on women's lives over years of serving their communities. These often take the form of 'home-grown interventions', such as the Healthy Love Workshop developed by SisterLove, Inc. in Atlanta, that was recently featured in the peer-reviewed journal AIDS and Behavior. These approaches confront root causes of vulnerability, such as gender-based violence, and provide access to a broad spectrum of services to reduce vulnerability and promote access, while teaching accurate and comprehensive information about sexuality and risk reduction strategies.

Achieving an effective HIV

prevention response for women will require building capacity of such organisations to continue this crucial work, and to partner beyond the HIV realm.

Achieving prevention justice for women demands first a commitment from the HIV community and federal agencies responsible for containing the epidemic to take the HIV crisis among women seriously.

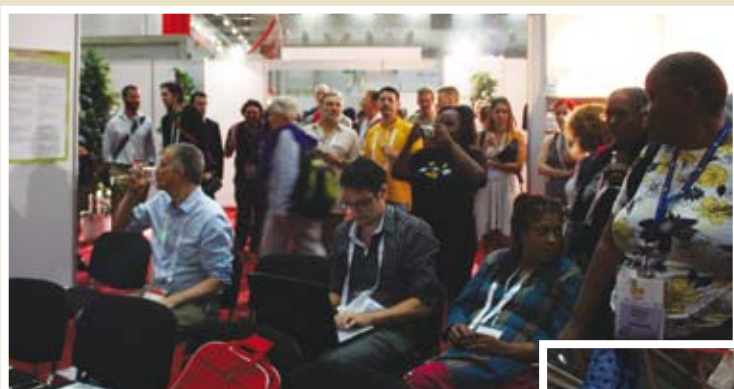
Achieving prevention justice for women will require research and investment to promote a structural and collaborative response to the HIV epidemic that truly upholds women's human rights, including locating comprehensive sexual and reproductive health services within HIV services. It will necessitate increased investment in HIV prevention overall, and implementing a more comprehensive and sophisticated system to target

and resource services for communities at structurally elevated risk for HIV – not just individuals who self-report behavioural risk. It will mandate increasing diversity, usability, accessibility and affordability of HIV prevention mechanisms that can be controlled by women.

Achieving prevention justice for women requires community leadership to create a social and political environment where women's health and right to access medical services is no longer an acceptable bargaining chip for political parties, but a reality. And, above all, it demands a continual commitment to address racial, gender, and economic injustice throughout the entire healthcare system.

*Naina is with Women Organized to Respond to Life-threatening Disease (WORLD), and Waheedah the Community HIV/AIDS Mobilization Project (CHAMP).*

**...an effective HIV prevention response for women will require... organisations... to partner beyond the HIV realm...**



Images...



and views...

\* Based on an interview conducted by Lauren Suchman

## In her own words...

# In conversation with Shari Margolese\*

Shari she has been an AIDS activist since she was diagnosed in 1993. When asked how the field has changed for women since her early days as an activist, Shari responded that in the beginning, 'we felt we were fighting for our lives; it was very urgent and immediate'. Activism and advocacy at this time focused on making drugs available and bringing them to market, a concern that was shared by both women and men. Now that drugs are widely available in Canada, activists and advocates have been able to focus specifically on the needs of women living with HIV. Shari has been involved heavily in advocating for the reproductive rights of mothers living with HIV in the past, and she is now turning her attention to developing an 'evidence base' in this area for fellow advocates and policy makers.

As Shari notes, many women living with HIV gave up their careers when they were diagnosed in order to become activists or volunteers working in the field of HIV and AIDS. These women are now at points in their lives where they are returning to the working world, partially out of necessity in order to support themselves and their families, but also because now their health allows them to do so. However, Shari notes that when confronted with

this decision herself, she wondered, 'what can I do in my professional life that's still going to be worthwhile?'. She decided to continue working in the HIV field with a new focus on research. Relating to her current job, Shari says, 'I am now advocating for the same things, I have been advocating for before. I'm still doing the same stuff, but I am busy creating a 'body of evidence' that will lead to policy change'.

Throughout our conversation, Shari repeatedly emphasised the importance of research on women living with HIV and on developing an evidence base. 'It's all well and good to wave a banner, and we need to do that, but if we don't have any evidence, it's going to fall on deaf ears'. She also pointed out that there is a real lack of evidence around women living with HIV, particularly regarding women's responses to medication.

Reflecting on the successes of the Women and HIV Research Programme, Shari believes that linking relevant stakeholders – community (service organisations as well as people living with HIV), infectious disease specialists, OB/GYNS, academics, and policy makers – has proven to be very effective. Some stakeholders have now become champions for the cause, since they are involved in the programme and know more about

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pregnancy planning for people living with HIV. The project itself, as pointed out by Shari, is structured according to a community-based model that promotes social justice and human rights, and also engages with the social determinants of health. And since the community of people living with HIV has been involved from the inception of the project, Shari says that the researchers can be sure they are addressing the questions that the community wants answered. According to Shari another success of this project has been to create opportunities for women living with HIV to start new careers, as the project employs these women as research assistants and project coordinators – I look back at 17 years ago and this would have been unheard of.

Although progress has been made in some ways, 'in other ways, we're back at where we started from', as women living with HIV in Canada still face a number of obstacles, and thus, 'evidence-based advocacy continues to be relevant and important'.

*Shari Margolese, Coordinator for the Women and HIV Research Program of the Women's College Research Institute, Toronto*

### Supported by the Oxfam HIV and AIDS Programme (South Africa)

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