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# Statutes undermine the progress made...

## The criminalisation of positive women

**Aziza Ahmed, Alice Welbourn, Beri Hull,  
Emma Bell, Heidi Nass**

*Criminalisation laws have a specific and nuanced impact on women living with HIV. An understanding of the consequences of such laws will help positive women and other advocates to combat negative uses of such laws, and to frame and advocate for effective alternatives for HIV prevention. This article helps tease out some of the ways that criminalisation can negatively impact the lives of positive women in particular: the explicit sex discrimination in the laws, the gender bias in courtrooms, the impact on marginalised women, and the increase in stigma and discrimination through criminalisation laws.*

### EXPLICIT DISCRIMINATION

*I dream of HIV positive women in Swaziland having the liberty to choose whether or not to conceive. Of having the freedom to engage in sexual relationships we want to, without fear or criticism from others.<sup>1</sup>*

Criminalisation of HIV refers to the use of HIV-specific criminal law or general law against transmission or exposure to HIV.<sup>2</sup> Most criminal law statutes, regardless of country and jurisdiction, contain similar language, which articulates the acts and mental states necessary to commit the crime of HIV transmission and/or exposure. While language that criminalises HIV transmission is largely found in broader national laws on HIV and AIDS, e.g. of Uganda<sup>3</sup> and Sierra Leone<sup>4</sup>, provisions criminalising HIV transmission can also be found in some sexual offences laws, including those of Kenya<sup>5</sup> and Rwanda<sup>6</sup>. Laws also criminalise both HIV transmission and exposure.

Criminalisation laws explicitly discriminate against women, because they have language which allows for

*Mujeres Adelante*

A NEWSLETTER ON WOMEN'S RIGHTS AND HIV

# Editorial...

**M**oving towards Vienna, this second issue in the series of special ALQ/ *Mujeres Adelante* editions on women's rights and HIV continues the discourse on some of the contentious issues and 'invisible' realities in the context of HIV risks, responses, and related rights-abuses.

The various articles raise the question as to how far we have come in not only recognising, but realising especially women's rights in the context of HIV and AIDS; and highlight some of the newly emerging challenges, as well as the existing challenges that continue to receive far too little attention in the response to HIV and AIDS. Some of the issues explored include the impact of HIV criminalisation laws on positive women; the extent to which HIV prevention efforts address the realities and needs of women; the accuracy of the female condom 'success' story in Zimbabwe; sex workers' involvement in HIV prevention work in Russia, as well as the 'invisibility' of transgender men.

This edition also provides an overview of latest legislative trends to further criminalise and/or prosecute same-sex relations in Africa; shares 'musings' on the Post-Beijing Framework; introduces a positive women's agenda for Europe and Central Asia; and includes a 'conversation' with Milly Katana.

Continuing the discussion on the impact of HIV criminalisation laws, **Aziza Ahmed, Alice Welbourn, Berri Hull, Emma Bell** and **Heidi Nass** explore the 'specific and nuanced impact' of laws criminalising HIV transmission and exposure on women. The article discusses various ways in which criminalisation laws impact negatively on the lives of positive women, including sex discrimination in the law itself; gender bias in the courtroom and the application of the law; targeting of marginalised women, such as sex workers; and increased stigma and discrimination. Analysing recent court cases applying laws that criminalise HIV exposure or transmission, the article argues that law reform is an essential step towards the realisation of positive women's sexual and reproductive health and rights.

Positive women taking the Namibian Ministry of Health to court on charges of unlawful sterilisation, is the focus of the article by **Jill Cole**. Reflecting on the 'pursuit of justice', she shares her court experiences, as well as information she obtained from interviews with women involved in the discovery of, and mobilisation around, the 'forced' sterilisation of positive women in Namibia. The article argues that since the fact of forced sterilisation has been established, the issue now is one of accountability and compensation.

In the context of criminalising sex and sexuality, **Michaela Clayton** discusses latest legislative developments in Uganda and Malawi. Looking at the proposed Anti-Homosexuality Bill in Uganda, as well as the prosecution of Monjeza and Chimbalanga in Malawi for engaging in same-sex relations, she argues that

*Continued on page 4*

## In this issue

1. **Statutes undermine the progress made...**  
*The criminalisation of positive women*  
Page 1
2. **Editorial**  
Page 2
3. **Non-negotiable: My body, my womb, my rights...**  
*Forced sterilisation of positive women in Namibia*  
Page 9
4. **Lack of evidence-based approaches...**  
*Criminalisation of same-sex relations in Africa*  
Page 12
5. **Remaining invisible...**  
*Transgender men and HIV prevention*  
Page 16
6. **Can we resist moving back to the future?...**  
*Musings on the Post-Beijing Framework*  
Page 20
7. **Moving beyond the commitments and rhetoric...**  
*HIV prevention interventions for women*  
Page 23
8. **Success story or numbers game...**  
*Female condoms in Zimbabwe*  
Page 29
9. **Very important, yet complicated task...**  
*Sex workers' involvement in HIV prevention in Russia*  
Page 35
10. **WECARE+...**  
*Moving forward the Positive Women's Agenda, linking across Europe and Central Asia*  
Page 40
11. **In conversation with Milly Katana**  
Page 46

only women to be targeted. Such is the case with laws criminalising mother-to-child transmission of HIV. Cases have also been brought against mothers for not seeking adequate care for their children during pregnancy, with specific regard to HIV after birth. The cases that have been brought against women also demonstrate a paternalistic attitude of the courts towards women who are positive and pregnant – often distrusting the opinions of the woman and her ability to care for her child or be responsible during her pregnancy.

Discrimination against women living with HIV is exemplified in the 2009 case of Ms. T. Ms. T, a 28 year old woman from Cameroon<sup>7</sup>, was arrested in the United States for falsified immigration documents. She was imprisoned for 114 days and should have been released under a ‘*time served sentence*’ with regard to her false documentation.<sup>8</sup> Upon finding out that she was living with HIV, the court elongated her sentence stating concern that the woman would not receive the medication necessary for the protection of her ‘*child*’, linking the lack of receiving medication to ‘*ongoing assault*’ from the mother onto the ‘*unborn child*’.<sup>9</sup> Largely due to the activism and advocacy of HIV

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towards women living with HIV and the belief that Ms. T would not act in a reasonable and rational manner with regard to the

rights organisations, advocates, and experts, Ms. T was eventually released. However, despite the eventual ‘*victory*’ of Ms. T, the case illustrates the distrust of the courts

health of her ‘*unborn child*’ (as HIV positive women might do), leading to an explicit discriminatory act towards Ms. T. This is separate from the stress (keeping in mind that she had just learned of her HIV positive status), anxiety, and unnecessary time under state supervision, which all constitute unnecessary hardship endured by women living with HIV.

This case also highlights other related ways women will be impacted by criminalisation: a) women are more often the caretakers (compared to men) and therefore more women will be left open to prosecution by governments for inadequate care, even when a mother has made a reasoned decision about her child’s health; and b) attacks on positive women in the form of accusing women of engaging in an ‘*ongoing assault*’ on their ‘*unborn child*’ is a crime specific to women living with HIV, as only a woman can carry this ‘*unborn child*’. Finally, while HIV is a contributing factor to the treatment of women in courts, the compounded stigmas of race, religion, and other minority or marginalised status, as it impacts the treatment of women, cannot be ignored.

#### GENDER BIAS IN THE COURTS

There is a bias against women in court proceedings. Women’s rights activists have long argued that even neutral laws are often applied unfairly against women, due to the patriarchal nature of courtrooms.

Perhaps the most illustrative case of gender bias in the court system, with specific regard to HIV, is that of a Canadian woman in Quebec (D.C.), who was recently charged with sexual assault and aggravated assault, because she did not tell her boyfriend (J.L.P.) she was HIV positive prior to engaging in sex.<sup>10 11</sup> D.C. laid a domestic violence charge on J.L.P. – he

there is a dire need for governments in Africa to support progressive and rights-based approaches to health and HIV prevention, instead of approaches that are *'based on prejudiced notions of morality'*. Thus, the article concludes that acknowledging same-sex relations is the *'only responsible way forward in HIV prevention'*.

Highlighting the *'invisibility'* of transgender men in HIV prevention, **He-Jin Kim** explores the HIV risks and vulnerabilities specific to this community. HIV prevention responses, as argued in the article, continue to fail the realities and needs of transgender men, based on a general lack *'understanding'* of who they are and why they are at risk of HIV infection combined with prevailing *'transphobic notions'* in society and service provision. For HIV prevention efforts to be responsive to transgender men's realities and risks, policies and programmes need to look past stereotypes and assumptions, and ensure that the factors determining their greater risks are adequately addressed.

In light of the upcoming Commission on the Status on Women in March 2010, **Tyler Crone** raises the question as to whether or not we can resist *'moving back to the future'*. Her *'musings'* on the post Beijing Framework assesses past achievements and disappointments for the women's health and rights movement; questions some of the progress made in the past 15 years; and looks into the future for new and sustained opportunities to build momentum and gain relevance. Recognising the progress made, she challenges the notion of *'established practice'* and concludes that *'we still have*

*farther to go'* and *'many more mountains to move'* to truly ensure that women's rights and health are recognised and protected.

Recognising the need to address women's HIV risks and vulnerabilities and to intensify HIV prevention efforts, **Johanna Kehler** and **Bongiwe Radebe** explore the progress made and challenges remaining in the context of HIV prevention for women, and raise the question as to where are the women-centred HIV prevention approaches. The article discusses available knowledge and *'evidence'* and argues that although the increasing commitment to recognise women's sexual and reproductive rights in the context of HIV and AIDS is commendable and crucial for effective HIV prevention efforts, it is high time to *'move beyond commitments and rhetoric'* so as to ensure that women's rights are not only recognised, but indeed realisable by women in the context of HIV prevention.

The lack of access to female condoms has long been the centre of debates. Responding to reports that Zimbabwe has one of the highest female condom distribution figures in the world, the article by **Lydia Mavengere** looks at the situation of women in Zimbabwe and questions the accuracy of the country's female condom success story. She explores the country's declining economic base and its impact on especially women's HIV risks, as well as the adequacy of the national HIV and AIDS response to women's realities and needs, and argues that given the country's socio-economic conditions combined with women's prevailing risks, Zimbabwe's female condom *'success'* story seems more a *'good case of playing the numbers game'*.

The importance of involving sex workers in HIV prevention work amongst sex workers is highlighted by **Irina Maslova**. Her article introduces the experiences of sex workers' involvement and equal participation in HIV prevention work amongst sex workers in St Petersburg, Russia. Sharing her own experiences in working with sex worker volunteers on issues of HIV prevention, she concludes that although a *'complicated task'*, sex workers' involvement and participation is essential for successful programmes and *'gives a precious experience'*.

Moving forward the positive women's agenda, **Alice Welbourn** introduces WECARE+, a newly established initiative of positive women in Europe and Central Asia. Illustrating the specific realities and needs of positive women in this region, including the lack of a positive women's agenda, she argues that the *'enormity of challenges'* positive women in Europe and Central Asia are facing need to be addressed so as to ensure a *'more humane response'* towards women with HIV.

And while the specific issues explored in the various articles may seem to differ, the common denominator is arguably one of recognising and protecting human rights, and particularly women's rights, in the context of HIV and AIDS. Similarly, despite the broad range of realities and needs presented in these articles, the common argument seems to be that as long as rights are not recognised, protected and realisable, HIV risks and vulnerabilities cannot be adequately addressed and HIV prevention efforts remain largely ineffective.

**JOHANNA KEHLER**

*Mujeres Adelante*

retaliated by charging her with assault, claiming that she did not disclose her HIV positive status to him. She stated that she did disclose, and in fact after her disclosure of her HIV status, they went on to have a multiple year relationship. Despite the fact that the first claim made was that of the domestic violence, the courts focused on the use of condoms during their sexual relationship despite the fact that J.L.P. never contracted HIV. The judge went on to determine that a condom had not been used, because D.C.'s physician reported that she had consulted with the physician about the risk of HIV transmission if the condom broke.<sup>12</sup> D.C. was eventually sentenced to one year in prison for sexual assault, for not informing her partner about her HIV status, while the court dropped all abuse charges against J.L.P.<sup>13</sup>

It is clear by the courts' analysis of the facts and eventual decision that the court felt that the one sexual encounter, which may have exposed someone to HIV (and did not lead to transmission of HIV), overrode the ongoing violence against a woman and her child, as articulated by the plaintiff in this case. While impossible to know each nuance of the case, we can, however, extract some very unsettling lessons about a positive woman's experience in court.

The first lesson: violence against women living with HIV does not always seem to be taken seriously. The court entirely ignored the domestic violence charge of the positive woman –

**...the vague language of the laws leaves great discretionary power...**

her life experience and words were entirely discounted in lieu of an accusation of exposure to HIV. The dismissal of violence against positive women sets a

particularly bad precedent: where an HIV positive woman is a victim of rape, and where potential transmission of HIV may

have occurred, the courts may choose to dismiss her experience of violence and focus on the exposure of the defendant to HIV. A second more general lesson:

seeking information about sexual transmission of HIV can be used against you in court, when you are living with HIV. Her desire to protect her partner and seek information in the event of a condom breaking was seen as inherently suspect and was used against her.<sup>14</sup>

There is bias in the courts against women that can lead to negative outcomes for cases brought against women living with HIV. Further, gender bias in the courts can undermine a desire to access services, and leave discouraged positive women from seeking help in abusive situations, including sexual violence.

**MARGINALISED WOMEN**

*...Police Force HIV Tests for Sex Workers...* – News Headline, Malawi, October 11, 2009<sup>15</sup>

*Vancouver HIV-Positive Prostitute Set to be Freed: Vancouver Police Don't Know Yet Whether They Will Be Issuing Public Warning* – News Headline, Canada, August 14, 2009<sup>16</sup>

*HIV-Positive Knoxville Woman a Walking Felony* – News Headline, USA, June 20, 2009<sup>17</sup>

Aside from the very existence of laws that criminalise

**...very unsettling lessons about a positive woman's experience in court...**

HIV, one of the core challenges with criminal transmission and exposure laws is the lack of clarity and specificity of the language in the laws that aim to describe intention. The vague language of the laws leaves great discretionary power in the hands of the government, policymakers, adjudicators, lawyers, the police and other relevant state agents who, as discussed, often come to know HIV through their own misunderstandings and bias. This discretionary power has often resulted in the targeting and further marginalisation of especially vulnerable groups, including sex workers, members of sexually diverse communities, and racial and ethnic minorities.

Precedent already exists for governments targeting specific marginalised communities, of which women are included. In Macedonia<sup>18</sup>, Egypt, India, and Senegal the respective governments have targeted sex workers, men who have sex with men, groups working with individuals living with HIV, and positive individuals themselves, through the use of laws which criminalise other behaviours, including same-sex relationships.

In some states of the United States, criminal behaviour is further punished when an individual is already engaged in an activity deemed illegal by the state. Colorado and Utah, for example, do not criminalise HIV, except as 'sentence enhancements' to other crimes of 'solicitation' and 'prostitution', as well as sexual offences.<sup>19</sup> The California Penal Code mandates HIV testing for individuals convicted of prostitution.<sup>20</sup> For some women, an aggravated charge of prostitution (for example, prostitution while living with HIV) means being placed on the sex offender registry that severely limits the ability to work and live in certain communities or get a job.<sup>21</sup> Perhaps best illustrative of the attitude towards sex

workers living with HIV is the coverage of the case of a positive sex worker in Knoxville, Tennessee, coined a 'walking felony'.<sup>22</sup> Women have also been arrested and charged in Ohio,<sup>23</sup> Florida,<sup>24</sup> and California<sup>25</sup> for sex work, while HIV positive.

Alongside the prosecution of individuals already marginalised by the law, where there are racial and ethnic minorities, an increase in policing and enforcement on behaviours deemed

criminal by the state result in the prosecution of racial minority groups.<sup>26</sup> In the United States, 70% of the prosecutions of pregnant women are directed against women of racial and ethnic minorities<sup>27</sup>, a telling fact with regard to the potential impact of transmission cases in the United States.

The ongoing targeted prosecutions aimed at already marginalised groups speak to the need to limit the ability of governments to arbitrarily apply laws. Criminalisation laws do the opposite – giving governments already guilty of marginalising certain groups the ability to do so further.

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## STIGMA AND DISCRIMINATION

*An HIV-positive French woman has been indicted for poisoning her boyfriend because she neglected to disclose her condition to him. An examining magistrate in the north-eastern city of Metz charged the woman on Wednesday after her 29-year-old boyfriend filed a lawsuit alleging she knowingly infected him with HIV during their three-year relationship.*<sup>28</sup>

For centuries various groups have been excluded from the realm of permissive sexual behaviour. The belief that control of sexuality and reproduction is necessary for broader societal control and order underpins the belief that some groups and individuals

are unworthy of exercising their sexual and reproductive health and rights. Criminalisation of HIV laws must be assessed for their impact on women's lives against the backdrop of

**...there is a bias against women in court proceedings...**

HIV positive women are irresponsible with regard to their bodies, their children, and their partners and therefore must be regulated. This idea is rooted in stigma and discrimination towards women living with HIV and is worsened by the criminalisation of HIV transmission and exposure.

Inflammatory newspaper articles and related media frenzy adds to the hysteria and unfounded notion that HIV positive individuals are purposefully attempting to infect other people with HIV, rather than engaging in consensual sexual exchange.<sup>29</sup> Women are often the targets of hysterical reporting and blamed for the spread of HIV – in one newspaper account, an HIV positive woman arrested for knowingly exposing others to HIV, the online website calls for all potential ‘victims’ to call a hotline. In another, a woman is referred to as a ‘threat to public safety’ for exposing sexual partners to HIV. This representation of HIV positive women enhances stigma and discrimination, and also affects the mental health of people with HIV,<sup>30</sup> thereby severely undermining their capacity to deal with their HIV status; and impacts also positive women's ability to access necessary sexual and reproductive health services.<sup>31</sup>

Stigma and discrimination also influence the courts and in turn the outcomes of cases. This bias and misunderstanding is exemplified by the sentencing of a positive woman to 21

months in prison for spitting on another inmate in her prison.<sup>32</sup> Such decisions are telling of the misinformation and misunderstanding regarding HIV that persist in courtrooms.

**CONCLUSION**

Criminalisation of HIV transmission and exposure laws crystallise discrimination against women living with HIV, and allow the state to intervene, halting the realisation of fundamental rights of women living with HIV.<sup>33</sup> The laws contain language that explicitly discriminates against women, that increases stigma and discrimination, and allows for especially marginalised women to be targeted by governments. Rather than help curb the spread of HIV, criminal law statutes undermine the progress made in the realisation of human rights, creates an environment that allows for ongoing violations of sexual and reproductive health and rights, and reverses gains made in addressing the HIV epidemic.

Understanding the nuanced interactions of women's lives and how they interface with the implementation of the law is a necessary step in calling for appropriate legal reform to enable the realisation of sexual and reproductive health and rights.

**...a paternalistic attitude of the courts towards women who are positive and pregnant...**

**FOOTNOTE:**

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*Aziza Ahmed is a Human Rights Lawyer and a member of the International Community of Women Living with HIV/AIDS (ICW); Alice Welbourn is the Founder and Director of the Salamander Trust; Beri Hull is the Global Advocacy Officer at the ICW; Emma Bell is the Research and Communications Officer at ICW; and Heidi Nass is the Director of the Treatment Education & Community Advocacy, HIV/AIDS Program at the University of Wisconsin in Madison, USA.*

*For more information and/or comments, please contact Aziza at aziza.ahmed@gmail.com.*

# Non-negotiable: My body, my womb, my rights... Forced sterilisation of positive women in Namibia

On a hot day in late November 2009, in the capital city of Windhoek, Namibia, close to forty women from the city's township of Katutura crowded into a small courtroom. They wore baseball caps and t-shirts emblazoned with fire-orange words that read, 'Non-negotiable: my body, my womb, my rights'.

## Jill Cole

The women had come in support of six women, who were taking Namibia's Ministry of Health to court on charges of unlawful sterilisation, and had been mobilised by members of the Namibian Women's Health Network (NWHN) and the International Community of Women Living with HIV/AIDS (ICW) in Namibia. Along with the Legal Assistance Centre, and other local and international NGOs, NWHN and ICW are spearheading the campaign against forced sterilisation in the Southern African country. What transpired in the courtroom that day guaranteed at least the pursuit of justice, for proceedings that had begun in October of 2009 were placed on hold, due to a legal point raised by the defence.

In October 2009, proceedings were halted when the Ministry argued that the charges brought against them fall under the purview of Article 33 of the Public Service Act of 1995, which posits that legal action against the Ministry must be filed within 12 months of the alleged activity, and that the Ministry must be notified of the action one month before charges are filed. At the present trial, an attorney from the Legal Assistance Centre deftly argued that the Public Service Act addresses relations between the government and its employees, not relations between the government and the public. Furthermore,

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considering the motion under the purview of the Act would set a standard that victims of, in the attorney's words, 'the most extreme invasion of the right to personality, to human dignity' are not worthy of compensation. The presiding Judge, even before ruling in the prosecution's favour, hinted at the outcome when he rhetorically asked the defence:

*Tell me, if a doctor had raped a woman under his care, would it also fall under the purview of the Public Service Act?*

I attended the trial with Veronika Kalambi, a member of the NWHN and ICW, where I had been assisting as an intern for the five weeks leading up to that day. Kalambi stated:

*After being at the courthouse, I am quite positive that the judge will be on our side ... If they say the case will go on, we will go on. But we have to push, we won't let them get away with this. If the ruling is not in our favour, we will not stop; the cases and documentation are building every day... Even if these six items are resolved in our favour, we still won't stop until the whole ordeal is dealt with.*

It is this tenacity and strength of purpose that members of NWHN and ICW bring to all campaign activities, which have included mobilisation of constituency members for a march on Katutura hospital, advocacy on their part to the Ministry of Health, and an ongoing dialogue with media outlets to raise awareness of the issue of unlawful sterilisation.

The NWHN and ICW learned of the problem in 2007 during routine discussions with constituency members. When a handful of young women came forward stating that they had been sterilised, without their knowledge or informed consent, the NWHN and ICW immediately took the issue to Namibia's Ministry of Health, which demanded evidence. This led the organisation to launch a research and documentation initiative targeting hospitals and HIV support groups. Out of two hundred support group members, a staggering forty women bravely came forward. From the 40 cases, the NWHN and ICW were able to use fifteen, and current litigation involves six. Many of the women's stories could not be included, because the statute of limitations had expired. 'Regardless', states Kalambi, 'we are still documenting, as women are still coming forward'.

I interviewed Kalambi about the organisation's role in the campaign to end forced sterilisation. While emphasising that 'this is not an organisation's issue, but one that belongs to everyone who cares', she went on to describe two focal points: women who may be potential targets of sterilisation (or those who are already victims of the practice) and the Ministry of Health.

*The role for us is to empower our women, to encourage*

**...they were literally threatened into signing, with hospital personnel refusing to treat them until they did so...**

*and help them to speak up. We want them to be empowered to talk, to face the doctor, to ask for information, to feel confident in asking, 'What are you doing to my body?'*

The power dynamics of the hospital encounter is pivotal, for a number of women who did sign forms consenting to be sterilised did so in the faith that their doctors knew what was best. Often, they themselves did not comprehend the term 'sterilisation', or they were presented with the forms amidst other 'routine' medical documents requiring a signature. In some cases, they were literally threatened into signing, with hospital personnel refusing to treat them until they did so. In speaking with hospital personnel, NWHN and ICW learned that every doctor was aware of the procedure, yet claimed not to know who performed it. According to Kalambi:

*...none of them denied it happened, and in fact, they defended it, asking, 'If a woman has ten kids and is HIV positive, what am I supposed to do with her?'*

**...sterilised, without their knowledge or informed consent...**

Kalambi continued:

*Our role is also to advocate for our members to the Ministry of Health. Normally, we have a good relationship with the Ministry. We want dialogue; we want to talk and to devise ways in which we can all improve. We want a working relationship; we are not meant to oppose the Ministry, but to work together.*

This last point is important, because as she went on to describe, individuals – especially women – who question government's activity can easily be accused of acting in opposition to the government. Late 2009 brought the fourth national election in Namibia, since the country gained independence in 1990, and

those working to end forced sterilisation had to be particularly cautious not to align the issue with party politics or to appear too critical of the government. Kalimbi comments:

*That's why some people were worried about me becoming involved ... The stigma is so high. But I decided that I will be involved, exactly because I am a full supporter of the ruling party. Even though what happened didn't happen to me, it hurts me. And who knows? It could happen to me, and if we don't address this issue, how many women who are not speaking out will continue to suffer?*

All the efforts have not gone unchallenged; when a South African TV crew entered Namibia to interview a woman on her experience of sterilisation, the organisation felt pressured to cancel the meeting.

Such setbacks only encourage those involved to be innovative in their arguments and approaches, and each encounter brings new facets of the issue to light. A point that Kalimbi continually returns to, is the apparently complete erasure of choice in the reproductive lives of Namibian women. Abortion is illegal except for 'extreme cases', and if a woman with little money wishes to be sterilised, the doctor will refuse on the basis that the procedure is 'too expensive'. In the current situation, the government and its employees take it upon themselves to decide who can – indeed, who must – undergo

these procedures, making HIV and womanhood a marker for discrimination.

*Sterilisation is one window into the gender-based violence that plagues our country... If the procedure is 'too expensive' for willing poor women, who is paying for positive women who are sterilised without their will, or even informed consent?*

For Kalimbi, the fact of sterilisation has been established, and there is no lack of evidence. The issue is now one of accountability, and the aim is not only recognising the fact, but also ensuring that victims be compensated. This includes clarification of the shadowy nature of the performed sterilisations.

Each of the six women is seeking 1.5 million N\$ in reparations, but Kalimbi also hopes for the women to be granted medical examinations to determine exactly how they were sterilised. If it is found that a given procedure is reversible, she hopes for the Ministry to pay for that surgery. As she states plainly:

*We don't simply want cash ... Cash does not buy secure relationships, dignity, and happiness.*

*Jill Cole is a Doctoral Student at the University of New York.*

*For more information and/or comments, please contact her at [jillpcole@gmail.com](mailto:jillpcole@gmail.com).*

# Lack of evidence-based approaches... Criminalisation of same-sex relations in Africa

Legislation introduced in Uganda in 2009 in the form of a Private Member's Bill by member of parliament, David Bahati, proposes extreme measures to 'establish a comprehensive consolidated legislation to protect the traditional family' and 'aims at strengthening the nation's capacity to deal with emerging internal and external threats to the traditional heterosexual family'.

**Michaela Clayton**

## UGANDA: CRIMINALISING SAME-SEX RELATIONS

It appears that Mr Bahati is not alone in this quest. The Anti-Homosexuality Bill has the backing of Ethics and Integrity Minister Nsaba Buturo, who has consistently spoken out strongly against homosexuality. He has been reported as stating that the proposed law would 'make Uganda a leader' in efforts against gay culture in Africa, and that 'on the issue of homosexuality, let them forget [about human rights]'<sup>1</sup>.

Buturo has also called for stricter laws to prosecute gays and lesbians in Uganda. At a press conference in 2008, he said:

*Who's going to occupy Uganda 20 years from now if we all become homosexuals ... We know that homosexuals don't reproduce. There is now a globalization of homosexuality and people in Uganda are attempting to take advantage of the globalization. It is an attempt to end civilization. It is that serious. We need to address this gap. We want it to become law in that if someone is a homosexual or confesses to being gay or lesbian, then he is a criminal.*<sup>2</sup>

In fact, the current law in Uganda already outlaws homosexual activity. Section 145 of the Penal Code Act provides that:

*Any person who: (a) has carnal knowledge of any person against the order of nature; (b) has carnal knowledge of an animal; or (c) permits a male person to have carnal knowledge of him or her against the order of nature, commits an offence and is liable to imprisonment for life.*

In practice, however, prosecutions are rare.

The proposed Anti-Homosexuality Bill defines 'the offence of homosexuality' in clause 2 in terms of men engaging in anal or oral sex or any person using 'any object or sexual contraption to penetrate or stimulate the sexual organ of a person of the same sex'.

It further states that the offence is committed whenever anyone 'touches another person with the intention of committing the act of homosexuality'.

Conviction, for actions 'against the order of nature', as prescribed under the current Penal Code, attracts life imprisonment. The Bill introduces a new offence of 'aggravated homosexuality' (Clause 3), for which the death penalty can be imposed. The offence of 'aggravated homosexuality' occurs where the offence of homosexuality is committed against a minor, someone in the offender's care or someone with a disability, or where the offender is living with HIV, is a serial offender, or drugs their victim.

The Bill also places an obligation on Ugandans to report

**...approaches to health that are not based on prejudiced notions of morality, but on evidence-based responses to the reality in our region...**

suspected offences of homosexuality or aggravated homosexuality. Anyone with *'power and control over other people because of their knowledge and official position'*, which explicitly includes *'a person who exercises religious, political, economic or social authority'*, has to report within 24 hours of becoming *'aware of the commission of any offence under this Act'*.

Failure to do so makes them liable to a fine or up to three years in prison (Clause 14). Thus, parents will be legally required to report their lesbian daughter or gay son to the authorities and teachers and doctors are required to denounce gay and lesbian pupils and patients.

The proposed Bill – if enacted into law – will threaten the achievements of Uganda in its response to HIV over the last 25 years, and as such goes against its purported aim of protecting the Ugandan people. The law will violate basic human rights, including the rights of people in same-sex relations, especially those living with HIV. It will not only undermine proven HIV prevention, treatment and care efforts focusing on vulnerable populations, such as men who have sex with men, but will also place the very same population at greater risk.<sup>3</sup>

Contrary to the provisions of Uganda's own Constitution, the Bill, in criminalising sexual acts between same-sex consenting adults, threatens to violate individuals' rights

**...arrest and prosecution of Monjeza and Chimbalanga not only undermine the responses to HIV...**

**...these statements have only served to drive this already vulnerable community further underground...**

to equality, autonomy, bodily integrity and privacy, and places unacceptable limitations on the rights to freedom of expression and association.<sup>4</sup>

The Bill will effectively allow the government to shut down civil society organisations, as well as media houses, which engage in any activities that are deemed to support *'homosexuality and*

*related activities'*. Thus, the Bill will have direct democratic and public health effects, as civil society organisations will no longer be able to legally advocate for the rights of, or even disseminate health information for, men and women engaging in same-sex relations.

Criminalising most-at-risk populations, such as men and women in same-sex relations, hinders HIV prevention by denying people education, methods and tools to practice safer sex, and might potentially amplify the epidemic in the general population.<sup>5</sup>

**MALAWI: PROSECUTING SAME-SEX RELATIONS**

In Malawi, existing law has been used recently to prosecute two Malawians for alleged same-sex sexual activity. On 28 December 2009, police officers arrested Steven Monjeza, 26, and Tiwonge Chimbalanga, 20, at their home charging them under Sections 153 and 156 of the

Malawian Penal Code for 'unnatural offences' and 'indecent practices between males'. This happened two days after Monjeza and Chimbalanga conducted a traditional engagement ceremony, an event that was widely reported in the Malawian press.

On 6 January 2010, they were taken to Queen Elizabeth Central Hospital, where Chimbalanga was forced to undergo a medical examination ostensibly to ascertain whether or not he had sexual relations with another man. The following day both men were subjected to a psychiatric evaluation. They are being held in Chichiri Prison in Blantyre and have been denied bail. Despite critical constitutional and legal issues raised by their lawyers in the High Court and to the Chief Justice as a Constitutional Court issue, the criminal trial continues. The penalty, if they are found guilty, is up to the maximum of 14 years in prison with hard labour.

This prosecution has caused widespread fear amongst persons engaged in same-sex relations – a group the Malawian government has recognised as vulnerable to discrimination and critical to its efforts to effectively respond to the HIV epidemic. The Malawian National HIV/AIDS Policy states:

*Government and partners shall put in place mechanisms to ensure that HIV/AIDS/STI prevention, treatment, care and support and impact mitigation services can be accessed by all without discrimination, including [persons engaged in same sex sexual relations].*

Dr. Mary Shawa, the Principal Secretary for Nutrition,

**...threaten the achievements of Uganda in its response to HIV over the last 25 years...**

HIV and AIDS in the President's Office also reportedly acknowledged the need to ...incorporate a human rights approach in the delivery of HIV and AIDS services to... men who have sexual intercourse with men.

She further asked men who have sex with men (MSM) to come out in the open in order to assist in HIV prevention efforts.

Given recent statements by governmental officials denouncing MSM, this is not going to happen, as these statements have only served to drive this already vulnerable community further underground.

The importance of reaching out to persons engaging in same-sex relations as a critical component of the response to HIV has been well-recognised by leading medical institutions, as well as UNAIDS, UNDP and the World Health Organisation. According to an August 2009 research paper published in the *Lancet*<sup>6</sup>, the world's leading medical journal,

*The HIV/AIDS community now has considerable challenges in clarifying and addressing the needs of [men having sex with men (MSM)] in sub-Saharan Africa... political and social hostility are endemic. An effective response to HIV/AIDS requires improved strategic information about all risk groups, including MSM. The belated response to MSM with HIV infection needs rapid and sustained national and international commitment to the development of appropriate interventions and actions to reduce structural and social barriers to make these accessible.*

The arrest and prosecution of Monjeza and Chimbalanga not only undermine the responses to HIV, but also constitute a gross violation of the fundamental rights enshrined in the Malawian Constitution. Specifically, the Malawian Constitution guarantees that every person has the right to liberty, human dignity, freedom and security of the person, and to be free from discrimination on all grounds. These rights guaranteed under the Constitution are reinforced under Malawi's regional and international legal obligations. The African Charter on Human and Peoples' Rights, ratified by Malawi in 1989, prohibits discrimination; provides for the right to equality; dignity; and liberty. Similarly, the International Covenant on Civil and Political Rights, which Malawi has also ratified, provides for freedom from discrimination; and the right to equality; liberty; and dignity.

HIV and human rights cannot be separated. Governments in Africa need to support progressive approaches to health that are not based on prejudiced notions of morality, but on evidence-based responses to the reality in our region. Acknowledging the existence of gay and lesbian people and providing supportive measures to assist men and women in same-sex relationships to make informed choices in their sexual health<sup>7</sup> is the only responsible way forward in HIV prevention<sup>8</sup>.

**...parents will be legally required to report their lesbian daughter or gay son to the authorities...**

**FOOTNOTES:**

1. [www.monitor.co.ug/artman/publish/news/uganda\_s\_toothless\_battle\_on\_gays\_93804.shtml]
2. On Top magazine, October 05, 2008.
3. UNAIDS. 2006. *UNAIDS Policy Brief: HIV and sex between men*. [http://data.unaids.org/pub/BriefingNote/2006/20060801\_Policy\_Brief\_MSM\_en.pdf]
4. Committee on Economic, Social and Cultural Rights. 2000. General Comment No. 14; Human Rights Committee, Toonen Decision (1994) and comments to states to repeal laws criminalising same-sex sexual activity; see also the Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, Document E/CN.4/2004/49, Para. 38.
5. UNAIDS. 2006. *UNAIDS Policy Brief: HIV and sex between men*. [http://data.unaids.org/pub/BriefingNote/2006/20060801\_Policy\_Brief\_MSM\_en.pdf]
6. Smith, A.D. et al. 2009. 'Men who have sex with men and HIV/AIDS in sub-Saharan Africa'. In: *The Lancet*. Vol 374, No 9687, pp416-433, 01 August 2009. [www.thelancet.com/journals/lancet/article/PIIS0140-6736(09)61118-1/fulltext#article\_upsell]
7. United Nations General Assembly Special Session, UNGASS. 2001. *Declaration of Commitment on HIV/AIDS*. Para 64; UNGASS. 2006. *Political Declaration on HIV/AIDS*. Para 20, 29.
8. UNAIDS. 2005. *Intensifying HIV Prevention*. Geneva, Joint United Nations Programme on HIV/AIDS. [http://data.unaids.org/publications/irc-pub06/jc1165-intensif\_hivnewstyle\_en.pdf]

*Michaela Clayton is the Director at the AIDS & Rights Alliance for Southern Africa (ARASA). For more information and/or comments, please contact her at michaela@arasa.org.na.*

# Remaining invisible...

## Transgender men and HIV prevention

**He-Jin Kim**

*When there is the scant mention of transgenders in HIV prevention policies and efforts, the term 'transgender' is often taken to be transgender/transsexual women.*

**T**his reference to transgender people happens mostly in the context of men who have sex with men (MSM). As UNAIDS defines MSM to include

*...self-identified gay, bisexual, or heterosexual men, many of whom may not consider themselves gay or bisexual. HIV responses for transgender populations are also often considered alongside MSM initiatives.<sup>1</sup>*

Considering transgender populations as a group alongside MSM initiatives, however, positions them very specifically in HIV prevention efforts alongside *cisgender*<sup>2</sup> men, an effective definition is placed as to their sexuality and gender – which, as argued, indirectly implies transgender women.

Very little mention is ever made of transgender men in HIV prevention. Yet, while there have been explorations as to sexuality and transgender men in queer and LGBT studies, such knowledge is rarely put in the context of the HIV and AIDS pandemics. For the

most part, studies considering transgender people and HIV, focus almost exclusively on transgender women, and often specifically on transgender women sex workers.<sup>3</sup> In fact, a review conducted by Melendez et.al. in 2006 found a total of 354 articles focused on 'transgender health', with only 12 articles specifically focusing on transgender men.<sup>4</sup> This falls short of what is actually needed in order to clearly address the risks transgender men face in the HIV and AIDS pandemics – an understanding that there is extreme diversity among transgenders, that transgender men sexually engage with people from diverse genders, and the societal context that affects their position in the context of HIV. Thus, for the most part it is largely speculations and stereotypes that dictate what kind of HIV prevention interventions transgender men are included in, if any. Such interventions, more often than not, are ignorant of the actual risks transgender men face, because they do not discuss the sexual acts they engage in and with whom.

### UNDERSTANDING TRANSGENDER MEN AND HIV RISKS

**...such knowledge is rarely put in the context of the HIV and AIDS pandemics...**

The term *transgender men* refers to transgender individuals who were born with a body that was socially defined to be 'female', but transition – socially – to live in a male/masculine gender role. They may opt for physical transition, and thus might opt for

hormone treatment and or bottom/top surgery, but this is hardly the norm. Therefore, when talking about transgender men it must be taken into account that we still are dealing with a demographic of people that can be as physically different from each other as a *cisgender* man and woman. For the most part, it

**...for the most part it is largely speculations and stereotypes...**

is the social aspect that defines the ‘maleness’ not the physical. However, when putting this in the context of HIV prevention, and thus in the context of sexuality, both the social and the physical must be taken into account, as both have a bearing on the sexual acts a transgender man might or might not opt to engage in.

Transphobic notions in society often hold that transgender men are not ‘*real men*’ and that they are merely very masculine lesbians. Also, like lesbian women, transgender men’s sexuality is considered to be not ‘*sexual*’ enough, and often considered to be low risk. This presumption is based on a stereotypical notion of what sexual acts a transgender man engages in and with whom they are considered to have sex with: women. However, like *cisgender* men, transgender men can be ‘*straight*’, bi or gay, while the sexual practices he engages in might vary depending on whether he is pre-, post-, or non-operative. This means that transgender men can be sexually

active both in lesbian and gay male communities, as well as in heterosexual communities.

Current dominating attitudes towards transgender men conceptualise them continually as female bodied individuals who engage sexually exclusively with other female bodied individuals.<sup>5</sup> This inherently poses a problem. Firstly, their bodies and specifically the perceptions of their own bodies are not ‘*female*’; and of course, they do not necessarily engage with women sexually. However, there is little attention to the sexual acts they engage in, and what risks they pose. Answers to questions, such as: ‘*what would a gay transgender male do in bed with another gay man?*’, and ‘*what risks are here at play in terms of HIV?*’ are clearly missing in many interventions.

While a transgender man may have a biologically defined ‘*female*’ body, he will avoid perceiving it as female. The perceptions transgender men have about their own bodies is important, because it influences what sexual acts they engage in, are willing to engage in, and how they talk about them. The fact that a transgender man might still have a vagina means that this may play a part in their sexual lives, though they might not refer to it as vaginal sex; neologisms such as ‘*frontal sex*’ or ‘*sex with their second hole*’ can be quite common. Such neologisms serve mostly to be able to be sexually expressive, to be able to enjoy sexuality with a body they do not identify with while maintaining their own gendered self, which in terms of transgender people can be essential to their own mental well-being. As such, the language and attitudes that transgender men adopt in terms

of their own bodies and sexuality must be taken into account when providing health services, including sexual and reproductive health services.<sup>6</sup>

Understanding the way transgender men talk about their bodies and thus, about the sexual acts they engage in, is essential in assessing the risks transgender men face in terms of HIV transmission, their understanding of HIV prevention needs, and how they can protect themselves. Realising that transgender men can engage in vaginal intercourse with another male, though they might not refer to it – or even experience it – as such when they do, adds another dimension to their need for sexual health information, and specifically in case of transgender men: reproductive health information. It also shatters many of the presumptions that exist about transgender men.

**HIV PREVENTION INTERVENTIONS FOR TRANSGENDER MEN**

Prevailing stigma and discrimination towards transgender men, combined with a clear absence in HIV prevention policies, pose a dangerous mix, as it only serves to further aggravate transgender men's risks of HIV infection. Violence towards transgenders is very high, and such violence, often sexual violence, should be seen in a gendered context. Transgender men, like lesbian women, are at

**...it is the social aspect that defines the 'maleness' not the physical...**

**...transgender men can face transphobic attitudes in the communities they are part of...**

risk of 'curative rape', since 'discovery crimes' – often when transgender men are living stealth – can take the form of 'punitive rape'. Such exposure to sexual violence, regardless of their sexual orientation, makes transgender men at least as a high a risk group as transgender women.

Further aggravating the issue is that transgender men can face transphobic attitudes in the communities they are part of. Acceptance of transgender men in lesbian communities is still a touchy issue, and fear of rejection of a community that they have been part of can be very real.

Even when able to access health services, the transphobic attitudes among service providers, or even just the sheer ignorance as to the issues they face, can discourage transgender men to access these services. There is also the dilemma of where to go, since services directed at women fail to acknowledge that transgender men are men, and this neglect of who they are is a strong barrier to accessing services in the first place, no matter what the attitudes of the staff might be. On the other end, if services directed at men are open to transgender men, they are not suitable to deal with a male person who was born with womb, vagina, cervix, and all the issues that come with it. Furthermore, transgender specific issues that might have an influence on

...we need to acknowledge the sexual rights of transgender men by making sure that HIV prevention policies address transgender men's realities and risks...

healthcare needs, such as hormone treatment and post surgery care, are usually not catered for.

policies address transgender men's realities and risks, as well as the barriers transgender men still face with regards to accessing sexual and reproductive health services. Thus, HIV prevention policies and programmes are to ensure that prevailing stigma, discrimination, violence and rape, which place transgender men at increased risk, are clearly addressed.

#### HIV PREVENTION RESPONSES

Even more so than transgender women,

transgender men are invisible in the context of HIV prevention.

There are no policies on any level that include transgender men's issues specifically. Even where transgender people, as a demographic, are mentioned in policies and programmes, transgender men – through a clear focus on transgender women, or male-bodied individuals – are by implication not included.

Recognising the 'invisibility' of transgender men, as well as the impact on their HIV risks, there is an urgent need to look past stereotypes, as well as the categories and boxes, which are often applied to transgender people in general. Instead of trying to define transgenders into groups of MSM and WSW, or even lump all transgenders together in one unified group, we need to look closer and consider actual sexual acts and the context in which they happen.

Even more than that, we need to acknowledge the sexual rights of transgender men by making sure that HIV prevention

#### FOOTNOTES:

1. [www.unaids.org/en/PolicyAndPractice/KeyPopulations/MenSexMen/default.asp]
2. 'Cisgender' is a term meaning the opposite of transgender.
3. Kenagy, G.P. & Hsieh, C.M. 2005. 'The risk less known: Female-to-male transgender persons' vulnerability to HIV infection'. In: *AIDS Care*. 17, pp1975-2007.
4. Melendez, R., Bonem, L. & Sember, T. 2006. 'On bodies and research: Transgender issues in health and HIV research articles'. In: *Sexuality Research and Social Policy: Journal of NSRC*. 3.4, pp21-38.
5. Adams, A. et.al. 2008. *Getting primed: Informing HIV Prevention with Gay/Bi/Queer Trans Men in Ontario*. AIDS Buireau, Ontario Ministry of Health and Long-Term Care.
6. *Ibid.*

*He-Jin Kim is an intern at the AIDS Legal Network (ALN).*

*For more information and/or comments,  
please contact her at [intern@aln.org.za](mailto:intern@aln.org.za).*

# Can we resist moving back to the future?...

## Musings on the Post-Beijing Framework

**E. Tyler Crone**

*So what will be the focus of attention and the 'hot topics' to be included in this post-Beijing era? What have the past fifteen years brought? Have we made great strides in achieving women's rights and health? Has there been another platform for women, which has met with breadth and depth of what transpired in Cairo or in Beijing?*

As an advocate whose 'coming of age' occurred as an intern busily working to support the US delegations to Cairo and Beijing, I share personal reflections on the challenges and opportunities at hand. I have borrowed the term 'back to the future' that a friend in the AIDS movement used to describe the scale-back of emphasis on the success of HIV treatment in global health circles, as I attempt to step back to assess the landscape of achievements and disappointments from the past fifteen years in a parallel realm, that of realising the ambitious agenda from Beijing.

I have more questions than answers – and await the discussions in New York City during the upcoming Commission on the Status of Women to test the validity of my hypothesis.

My quiet fear is that we have not sprouted the vast and far-reaching movement for women's rights and health that appeared at hand in the mid-1990s. My quiet fear is that we have not evolved our thinking or strengthened our numbers, because we have not yet expanded our tent and opened our doors sufficiently to allies in related movements.

In a recent briefing with colleagues from across the sexual and reproductive health and rights and HIV fields on the upcoming Commission on the Status of Women this year, the main discussion points centred around the issues that seemingly remain unchanged, such as abortion rights and youth sexuality education. There was talk of 'the

*opposition'* – and questions from my colleagues in the Global South as to just what or who 'the opposition' might be. There were fears of plastic foetuses – and debate around whether or not this review would have any 'teeth' or hold any weight in the

system of UN norm setting and governmental action.

This year's Commission on the Status of Women comes at a time where millions of women die needlessly of maternal complications; where millions of women are grappling with HIV in their every day; where the recognition of marital

*...we have not yet expanded our tent and opened our doors sufficiently to allies in related movements...*

rape or property and inheritance rights remain contested; where legislative trends are to criminalise HIV transmission and exposure to the particular detriment of women; and where there is renewed homophobia, with violence directed toward lesbian women, and laws that perpetuate stigma, discrimination, and hostility based on sexual orientation.

How far have we come when national protest and debate in Kenya centres on a constitutional change to identify life as beginning at conception? How far have we come when an abortion provider in the United States is murdered at his church on a Sunday? How far have we come when HIV groups in Swaziland and Uganda face pressure from women's legal groups or sexual and reproductive health and rights entities for advocating for LGBT rights? How far have we come when trends indicate that women's work has only grown with increased education and formal employment outside the home?

The issues are both personal and political. I look through a mixed lens of gender, human rights, sexual and reproductive health and rights, and HIV to wonder why women living with HIV face coerced sterilisation through national 'PMTCT' programmes in Namibia; to wonder how funding conditions, such as the anti-prostitution pledges, ever came to be; to

wonder why new contraception or HIV prevention tools for women remain scarce; and to wonder why fundamentals, such as women's agency, voice, and dignity, remain a site of struggle where there is a need for constant engagement rather than established practice.

Can a movement be built from a focus on safe, legal abortion without inclusion of and attention to safe, legal motherhood or safe, legal pleasure? I have intentionally used

a framing of 'safe and legal' for as I have suggested above – there are significant trends for motherhood to neither be safe nor legal for women living with HIV or for pleasure to be safe or legal for women who love women. What of it being

*...to wonder why fundamentals, such as women's agency, voice, and dignity, remain a site of struggle...*

novel that men and boys be advocates for gender equality or be involved in antenatal care? What of it being novel that maternal mortality is articulated as a health and human rights issue? What of it being novel that renewed attention is given to a woman's agency at the UN or to a large scale plan to address women, girls, and gender equality through UNAIDS? Are the mechanisms of change really this slow?

My hypothesis is that the women's health and rights movement has been too narrow to draw in diverse and far reaching constituencies, whether it be women of colour in the United States, sex workers in India, women who use

drugs in Russia, or women living with HIV in Namibia. My hypothesis is that we have failed to collectively reach out and evolve – and have developed an **over-invested stake** in ‘our’ issue, failing to see ‘our issues’, as they intersect in lived reality. While we have begun to see cross-cutting efforts to link sexual and reproductive health and rights and HIV or to engage multiple feminisms, we still have farther to go. There are many more mountains to move by expanding our gaze and reaching out our hands. There are new civil society leaders to support and political leaders to hold to account.

*...too narrow to draw in  
diverse and far reaching  
constituencies...*

And as for the 2010 Commission on the Status of Women, these are the questions I will be seeking to answer in this post-Beijing era:

- 1) Does the political will of today surpass or even simply meet the political will evident fifteen years ago?
- 2) Are new faces present? Have we mentored the next generation of advocates? Have we expanded our ranks to bring those from the margins to the centre? Has our movement grown to include women (and men) in all their diversity?

- 3) What is the most pressing nexus of issues? Where are the opportunities to build momentum? To gain relevance?

I still hold true to old slogans that have framed this movement – women’s rights are human rights, women’s health is world health.

*E. Tyler Crone is the Coordinating Director of the ATHENA Network. For more information and/or comments, please contact her at [tyler.crone@gmail.com](mailto:tyler.crone@gmail.com).*

# Moving beyond the commitments and rhetoric. . .

## HIV prevention interventions for women

*For many years, data clearly indicates that women are the ones most infected and affected by HIV and AIDS; that women are at disproportionate risk of HIV infection; and that women are more likely to be subjected to HIV-related stigma, discrimination and other violation of rights*

**Johanna Kehler, Bongiwe Radebe**

**F**or many years, data clearly indicates that women are the ones most infected and affected by HIV and AIDS; that women are at disproportionate risk of HIV infection; and that women are more likely to be subjected to HIV-related stigma, discrimination and other violations of rights. In recent years, there is also growing evidence of especially positive women's sexual and reproductive health and rights violations; with cases of coercive sterilisation of positive women in Namibia being but one of the examples of gross human rights violations. Yet, national and global responses to especially women's HIV risks and vulnerabilities, and related rights abuses, continue to be mostly inadequate in responding to women's realities and needs – thus failing to address women's risks and vulnerabilities. Moreover, while it is increasingly acknowledged that HIV prevention efforts have to be scaled-up, effective HIV prevention interventions addressing specifically women's risks seem few and far between.

### KNOWLEDGE, EVIDENCE AND COMMITMENTS

According to latest available data, half of the adult population living with HIV worldwide (33.4 million) are women; and 60% of all positive women live in Sub-Saharan Africa.<sup>1</sup> At the same time, data indicates that the number of new HIV infections

seem to 'override' the advances made in providing access to treatment, since for every two people placed on treatment five become newly infected with HIV;<sup>2</sup> thus, concerted efforts are required to scale up HIV prevention.

Moreover, the complexity of women's HIV risks and vulnerabilities, as well as the need to address their underlying factors, are well recognised. As re-affirmed by UNAIDS [2009:6]:

*The increased vulnerability of women and girls to HIV infection stems from biology and from social, economic, legal and cultural factors such as entrenched gender roles, unbalanced power relations, disproportionate burden of AIDS-related care and the occurrence, and societies' acceptance of, violence against women, including sexual coercion.*

There is also growing acknowledgment that an effective response to HIV and AIDS requires that human rights are at the centre of all programmes and interventions. More specifically, there is the recognition that

*In order to effectively curb the HIV epidemic, national responses need to more systematically address the rights and needs of women and girls. [UNAIDS, 2009:11]*

And finally, numerous commitments have been made over the years at a national, regional and global level to address women's rights and needs; including the Beijing Declaration

and Platform for Action (1995), the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW, 1979), and the UNGASS Declaration of Commitment on HIV/AIDS (2001). Whilst the adequate translation of these commitments into programmes and interventions that truly address women's realities, rights and needs seems to be absent, these commitments, as argued by UNAIDS [2009:1] offer a 'sound basis' for renewed calls to:

*...creating enabling environments for upholding women's human rights and addressing the needs of women living with HIV, as well as providing strong focus on comprehensive prevention approaches to HIV, sexual and reproductive health, and violence against women.*

The recognition of women's risks, the calls to protect women's rights and to address women's HIV risks and vulnerabilities in all their complexities are commendable. Still, despite the knowledge, 'evidence' and commitments, HIV prevention efforts seem thus far to fail their declared target of decreasing especially women's risks and vulnerabilities, and creating enabling environments for women to equally access, participate in, and benefit from available HIV prevention strategies and tools. Or, as concluded by UNAIDS [2009:1]

*Despite these significant commitments to promote and protect the human rights of women and girls, the HIV epidemic continues to reveal a gap between rhetoric and reality.*

**...effective HIV prevention interventions addressing specifically women's risks seem few and far between...**

## **HIV PREVENTION EFFORTS AND REALITIES**

Given all the 'evidence' and commitments, it could be argued that the response to HIV and AIDS in recent years should have been marked with the rapid increase in women-centred and women-controlled HIV prevention interventions and methods; should have seen drastic increases in resource allocations for HIV prevention tools for women; and thus, could have seen a decrease in women's risks and vulnerabilities. Instead, HIV prevention efforts have neither been centred around women's realities, rights and needs, nor are women placed in the position to have control over decisions regarding their own HIV risks, as HIV prevention approaches continue to focus on 'ABC', and resources, if at all, are more likely to be allocated to the promotion and distribution of male condoms. Moreover, despite the recognised need to address the societal context that determines and perpetuates women's risks and vulnerabilities little has been achieved in transforming societies and creating enabling environments for women. UNAIDS [2009:1] further states that

*...persistent gender inequality and human rights violations that put women and girls at greater risk and vulnerability to HIV, continue to hamper the progress and threaten the gains that have been made in preventing HIV transmission and increasing access to anti-retroviral treatment.*

## **PREVENTION STRATEGIES**

Whilst stressing the imperative of multi-faceted approaches

to HIV prevention, which would range from increasing levels of awareness and knowledge about HIV risks to promoting behavioural change and increasing condom use, the 'ABC' approach to HIV prevention still seems to be the foundation of most HIV prevention efforts. As such, the concept of promoting 'abstinence' and/or delayed sexual debut for young people, faithfulness for married and/or cohabiting couples, and condom use for young people who cannot abstain or couples who are not faithful prevails, despite all the knowledge and 'evidence' to the contrary. As early as 2005, data<sup>3</sup> suggested that the 'ABC' prevention approach not only fails to have the desired impact, but also that women's risks and vulnerabilities are further entrenched by the failure of HIV prevention strategies to address the underlying

**...little has been achieved in transforming societies and creating enabling environments for women...**

often lack the desired impact, as they fail to be accompanied by scaled-up condom promotion and distribution. As such, HIV prevention efforts often appear to lack the necessary urgency to address and respond to HIV risks and vulnerabilities 'now and here'. Recognising behavioural change and societal transformation as critical aspects of effective prevention responses, arguably, also requires

that HIV prevention tools are readily available and accessible during the 'process of change', so as to ensure that especially risks and vulnerabilities are addressed effectively.

**EFFECTIVE PREVENTION METHODS**

Condoms are proven to be an effective prevention tool. Yet, condom availability, access and use continue to be major challenges in HIV prevention, especially in high-prevalence countries, such as South Africa. Moreover, the general lack of female condom promotion and availability is yet another example of HIV prevention efforts that fail to place women's realities and needs at the centre, and to create an enabling environment for women to have control over HIV prevention. According to UNAIDS [2009:11]:

*The lack of female control of prevention is evidenced by the fact that currently one female condom is distributed for every 700 male condoms.*

Common 'excuses' of female condoms being too costly still prevail, even though a lower cost second generation female condom, the FC2, has been approved and is available at 30% less than its earlier version<sup>3</sup>. So, even without an increase in

factors and 'drivers' of the pandemics, such as gendered inequalities and power relations. Yet, HIV prevention responses still appear to primarily rely on the principles of this approach.

In reality, more efforts and resources

**... 'behavioural change programmes' often lack the desired impact, as they fail to be accompanied by scaled-up condom promotion and distribution...**

seem to be directed towards 'abstinence and faithfulness' programmes, than on increasing condom distribution and use. At the same time, 'behavioural change programmes'

resource allocations for female condom distribution, more female condoms should be available. Yet, the question remains: ‘*where are the female condoms?*’<sup>5</sup>, and where is the long-awaited implementation of commitments to address women’s HIV risks and vulnerabilities?

While these questions are yet to be answered, women continue to be at greater risk of HIV infection, with male condoms as the only prevention ‘*tool*’ available. Rights advocates calling for the availability of female condoms have long made the argument that government’s failure to provide adequate access to female condoms constitutes a human rights violation, including a violation of women’s rights to make an informed decision about whether or not, with whom and how to engage in sex. In the context of commitments to address especially women’s risks and vulnerabilities to HIV, the distribution of male condoms, while at the same time recognising women’s ‘*lack of power*’ to negotiate condom use, seems a rather insignificant effort to address women’s HIV risks and vulnerabilities; as women continue to be more ‘*passive recipients*’ of men’s prevention choices, as compared to become ‘*active agents*’ in HIV prevention choices for women.

### **WOMEN’S SEXUAL AND REPRODUCTIVE RIGHTS AND CHOICES**

The promotion and protection of women’s sexual and reproductive rights and choices are key to effective HIV prevention responses. Yet, prevention interventions and programmes that go beyond the commitment to recognise

sexual and reproductive rights and choices of women, and that are indeed premised on the realisation of women’s sexual and reproductive rights, remain scarce. Furthermore, while interventions and programmes designed to afford women the

enabling environment to claim sexual and reproductive rights may be in place, the lack of adequate implementation of these programmes combined with prevailing stigma, discrimination and rights abuses greatly impact on women’s ‘*ability*’ to claim their sexual and reproductive rights and to access related services. Access to HIV prevention information and choices,

including access to prevention of vertical transmission of HIV programmes, is but one of the examples of available programmes lacking adequate implementation and thus, failing to guarantee the protection of women’s sexual and reproductive rights.

The extent to which women are in the position to claim their rights in the context of programmes designed to prevent vertical transmission have been questioned and debated for quite some time. Notwithstanding the progress made in the provision of these services, latest evidence<sup>6</sup> suggests that, despite these efforts, programmes are largely ineffective and failing to reach women in need of services. It has been argued that the lack of effectiveness of prevention of vertical transmission of HIV programmes is due to its sole focus on

*...providing antiretroviral prophylaxis to prevent the transmission of HIV to newborns and not on other essentials – such as prevention, counselling, care and*

**...a rather insignificant effort to address women’s HIV risks and vulnerabilities...**

*treatment services for women and children.*<sup>7</sup>

### ...to move beyond the commitment and rhetoric...

The inadequate implementation of these programmes not only denies women their right to sexual and reproductive health, but also calls to question the extent to which women's rights are at the centre of HIV prevention programmes. Arguments have also been made<sup>8</sup> that the current design and implementation of prevention of vertical transmission of HIV programmes seems to compromise women's rights at the expense of the right of the 'unborn child'; even more so with the introduction of 'opt-out' HIV testing in antenatal care, further threatening women's rights to autonomy, informed consent, confidentiality and non-discrimination.

Responding to these realities, new commitments<sup>9</sup> have been made to increase women's access to HIV treatment, care and support in their own right and to ensure that women's rights are protected in antenatal care facilities, and beyond. However, the translation of these new commitments into reality has yet to be seen.

One of the extreme women's rights abuses is, arguably, the occurrence of forced sterilisation of positive women, which has been well-documented by ICW and others<sup>10</sup>. It is important to bear in mind that

this gross human rights violation of positive women's sexual and reproductive rights occurs in the realm of HIV prevention programmes. In Namibia, more than 40 cases of 'forced' sterilisation of positive women have been recorded; with six of the cases currently pursued in court, positive women suing the Ministry of Health for unlawful sterilisation

*...they were in pain, they were told to sign, and they didn't know what it was. They thought it was part of their HIV treatment...because it was never explained to them.*<sup>11</sup>

There is also a growing knowledge base of cases where positive women are 'forced' to consent to termination of pregnancy procedures, given limited access to contraceptive options and/or are denied access to sexual and reproductive health services.

While practices like these are not necessarily to be found in policies guiding the response to HIV and AIDS, they are nevertheless part of women's prevention realities, and arguably premised on rather common beliefs that

especially positive women should be 'prevented' from exercising their right to engage in sex, to have children, and to make informed choices about matters of sex, sexuality and reproduction. Subsequently, despite the commitment to women's sexual and reproductive rights, women's realities continue to be filled with sexual and reproductive rights violations; further perpetuating and reinforcing women's HIV risks and vulnerabilities.

**...prevention interventions and programmes ... that are indeed premised on the realisation of women's sexual and reproductive rights, remain scarce...**

## CONCLUDING REMARKS

As indicated, there seems to be no lack of commitment to address women's rights, realities and needs. There also seems to be no lack of a commitment to intensify HIV prevention efforts, nor a commitment to recognise women's sexual and reproductive rights and choices. Yet, women's rights and needs are seldom addressed in the response to HIV and AIDS; HIV prevention efforts continuously fail to provide prevention

**...create a truly enabling and supportive environment for women 'to take control of their own HIV prevention'...**

options that are centred around women's needs and that are controlled by women; and thus, women's sexual and reproductive rights remain to be violated, limited, and/or denied.

It is hence argued that what is urgently required to effectively address women's HIV risks and vulnerabilities and to afford accessible prevention options for women, is to move beyond the commitment and rhetoric; to rigorously start translating the knowledge, evidence and commitments into programmes and practices that are of direct benefit to women; and to create a truly enabling and supportive environment for women 'to take control of their own HIV prevention'<sup>12</sup>.

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Johanna Kehler is the Executive Director and Bongiwe Radebe is a Facilitator at the AIDS Legal Network (ALN). For more information and/or comments, please contact Johanna at [jkaln@mweb.co.za](mailto:jkaln@mweb.co.za).

# Success story or numbers game . . . Female condoms in Zimbabwe

**Lydia Mavengere**

Since the 1990s, Zimbabwe has recorded a declining HIV prevalence, from a peak of 26% in 2001, to the country's latest HIV prevalence figures, which now stand at 13,7% in 2009.<sup>1</sup> Zimbabwe is also lauded to have the highest female condom distribution figures in the world.

*If there is a female condom success story, it is Zimbabwe, which boasts the highest rate of female condom distribution per capita worldwide, according to UNFPA country office estimates. In 2008, the government and partners distributed over five million of the condoms.<sup>2</sup>*

However, we must ask what this praise of Zimbabwe's female condom distribution means for Zimbabwean women. As reports of a continued decline in HIV prevalence are coming in, are

**...could the female condom distribution 'success' story simply be a good case at playing the numbers game?...**

groups requiring the condoms. Consequently, despite this drop in HIV prevalence, incidences of HIV are still high throughout

women in Zimbabwe in a better position to deal with HIV, than in the 1990s? The argument is that per capita distribution does not necessarily translate into equitable distribution amongst the respective demographic

the country. Zimbabwe's response to HIV has lacked coordination and as a result, a number of knowledge gaps remain. Women are still largely marginalised and at high risk of HIV infection.

## BACKGROUND: THE ZIMBABWEAN SITUATION

This article argues that the prevailing economic situation places women at greater risk of HIV infection. Moreover, an internal situation of disturbance has existed in Zimbabwe since the 'land redistribution' in 2000. Whilst farm invasions resulted in massive movements of people, with families becoming homeless, without a source of income, the year 2005 saw the implementation of 'Operation Murambatsvina', a purported clean-up operation that resulted in the destruction of thousands of homes and small business operations in major cities throughout Zimbabwe. As a result,

*...by July 2005, it was estimated that Operation Murambatsvina had displaced some 700,000 people, including over 79,500 adults living with HIV.<sup>3</sup>*

Taking into account the fact that up to 80% of people living with HIV are not aware of their HIV status, this number could be much higher.

Today in Zimbabwe, a new wave of land grabs and occupations have begun. The Zimbabwe Mail reported in September 2009 that:

*At least 223 cash-strapped farmers are being prosecuted for 'failing to vacate' their farms and are battling to foot the US\$1.5-million legal bill.<sup>4</sup>*

This will result in hundreds more families of farm workers being displaced, left homeless, and without a source of income.

**A DECLINING ECONOMIC BASE IN ZIMBABWE**

In a country with an 80% unemployment rate, and an average salary of US\$150 per month for those employed, the reality is that women are at an even greater risk of HIV infection, as a result of the prevailing violence and instability. At the end of the day, the female condom distribution ‘*success*’ story is indeed very impressive; however, evidence on the ground speaks otherwise. A failing health delivery system and a government that is preoccupied with the business of ruling at the expense of its own people, has kept Zimbabwean women marginalised and without access to basic health facilities. Given the situation, it would follow that putting aside money to buy condoms, especially female condoms, appears rather farfetched.

According to the Zimbabwe National AIDS Strategic Plan (2006-2010), 92% of HIV transmissions in Zimbabwe occur

**...the stigmatised nature of female condoms, whose use is often associated with commercial sex workers and/or casual relationships...**

through heterosexual intercourse. 55% of people infected with the virus are women, and of the estimated 135,000 new adult (15 to 49 years) HIV infections during 2005, 58% were women<sup>5</sup>. Young women aged 15 to 29 years old are the most

vulnerable, and it is estimated that the ratio of young women living with HIV is three times higher, as compared to men the same age.<sup>6</sup>

Consequently, women in all groups, young, old, single or married, are the most vulnerable for a number of reasons.

According to the latest UNAIDS report about Zimbabwe, the percentage of young people aged 15-24 years that had sex with more than one partner in the last 12

months is estimated to be 7.1% for males and 0.9% for females<sup>7</sup>. Furthermore, cultural norms make condom usage negotiation difficult for women in any heterosexual relationship. This is evidenced by the fact that condom use was reported to be lower for women who engaged in ‘*high risk*’ sex (45.6%) than men at (71.0%) in the 15 -49 year age group.<sup>8</sup>

Essentially, what these figures say is that men are more prone to multiple sexual partners than females; yet men are more likely to use condoms than women. Effectively, women who are married, or in long-term relationships, are on the receiving end of male partners who engage in multiple sexual partnerships.

**THE STRUCTURE OF THE HIV RESPONSE IN ZIMBABWE**

While some efforts have been made in responding to HIV in Zimbabwe since the early 1990s, this has been mostly on the part of civil society. While survey results indicate a fall in Zimbabwe’s adult HIV prevalence, this data should not be taken at face value; the large numbers of displaced people in Zimbabwe questions whether or not the demographics presented in statistics are indeed representative, since AIDS deaths and migration could have played a role in the decline in HIV prevalence.<sup>9</sup>

The hard facts, arguably, demand that greater effort be put into the HIV response at a national/government level. In this case, it means that more female condoms should be distributed

**...how many women can indeed afford to buy a single female condom, when they can barely afford to buy food...**

freely, as is the case with male condoms. Yet, the emerging picture is one of an effort dominated by civil society.

Events surrounding the 2008 elections when most NGOs were not allowed to carry out their work resulted in many programmes either down-scaling operations or simply moving to other countries. In addition Zimbabwe received a grant in the 8th round of funding by the Global Fund, but this money has not been given to the National AIDS Council, but instead to the United Nations Development Programme, which had major consequences for the government's management of the HIV programme.

### DONOR DEPENDENCY

Zimbabwe's HIV response is mainly donor funded; yet

*...despite having one of the world's highest HIV prevalence rates, Zimbabwean proposals to the Global Fund to Fight AIDS, Tuberculosis and Malaria have been turned down in five of the Fund's eight funding rounds since its formation in 2002. According to Zimbabwe's latest UNGASS report, the National AIDS Council, which is responsible for a 3% tax levy collected from all employees and businesses, provided \$83 750.<sup>10</sup>*

Compared to the 2008 funding from PEPFAR (\$24,4 million) and Global Fund (\$79 million)<sup>11</sup> this would be 0,08% of the money invested into the HIV response by government.

Furthermore, difficult working relations between government and civil society have made it more challenging for new funders to come in.

*In Zimbabwe, despite the glaring humanitarian crisis, MSF often*

*experiences restrictions and enforced delays when carrying out its work. There is a clear lack of a strong, coordinated, international response to the unfolding humanitarian emergency.<sup>12</sup>*

Zimbabwe has received a lot less funding than its neighbours, with similar HIV prevalence rates. Zimbabwe also diverted \$7 million of a \$39 million Global Fund grant to sponsor its elections in 2008. While the money was eventually returned, this demonstrated a lack of discipline on the part of government, and even worse, a lack of commitment to the HIV response.

While it is acknowledged that a lot of developing countries manage their HIV programmes with donor funding, donor funds do come with their own conditions. In the case of PEPFAR, Sippel [2008:7] notes that

*...perhaps most significant deterrent for both male and female condom distribution within US policy, however, is the congressionally mandated requirement that 33% of prevention funds under the President's Emergency Plan for AIDS Relief (PEPFAR) must be spent on 'abstinence-until-marriage' programmes.*

As a result condom promotion is confined to high risk groups 'stigmatising condom use and leaving married women and youth at particular risk of HIV infection'<sup>13</sup>.

For any country to successfully manage its HIV and AIDS epidemics, a healthy balance is required between government generated funds and donor funding. Government's role in that particular case would be to come up with a system to fill in the gaps not funded by donors, as well as conduct research to ensure that all responses are adequate and timely.

As a result of this donor control of the

**...the 'sale' of female condoms ... places women at an even further disadvantage...**

HIV response, and in particular female condom distribution in Zimbabwe,

*...there has also been conflict between the messages promoted by different programmes; for instance, some religious or traditional campaigns discourage the use of condoms and place emphasis on abstinence, contrasting with the strategies of some other organisations. This has led to confusion about how it is best to prevent HIV infection, particularly amongst young people.*<sup>14</sup>

This, arguably, also explains the relatively higher HIV incidence rate amongst the 15 to 24 year olds and in particular, females in that age group.

The Zimbabwe NSP notes that there are growing incidents of married women with HIV.

*Recent studies have highlighted the high vulnerability of married women to HIV infection. A review of behavioural change approaches revealed that marriage alone is not a protective factor, as extra-marital relationships are frequent, couple communication difficult and the disclosure of one's HIV status is irregular. In addition condom use in marriage and with regular partners is low.*<sup>15</sup>

Low condom use amongst women is also impacted by the stigmatised nature of female condoms, whose use is often associated with commercial sex workers and/or casual relationships.

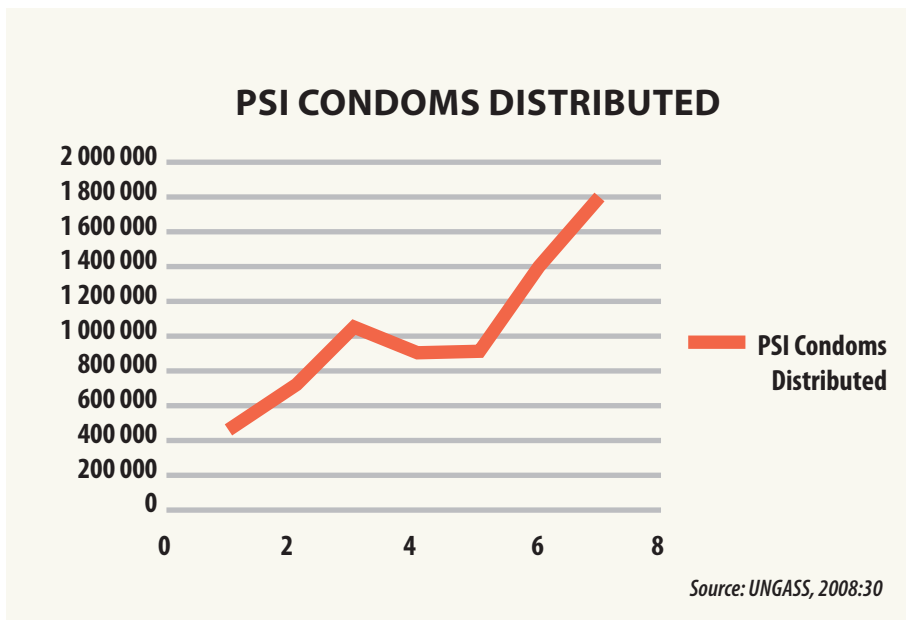
Behaviour change programmes have been implemented for

over 15 years, but despite the body of evidence that has been accumulated, most programmes in Zimbabwe have not been research-based. This includes interventions targeting young people, which are not tailored to their specific needs, as programmes and interventions do not take adequately into account differences in age, sex, and previous sexual experience.<sup>16</sup>

**CONDOM DISTRIBUTION**

Sales of female condoms were first introduced in Zimbabwe in 1997 and had risen by almost 60 percent by 2007.<sup>17</sup> However, in the context of the worsening financial position for Zimbabwe, these stated figures would, arguably, require further analysis.

The Zimbabwe National Strategic Plan cites that more



than 85 million male condoms were distributed and/or sold in 2004, 37 million within the public sector and 48 million in the social marketing sector. Furthermore, 353 600 female condoms were distributed<sup>18</sup> and 750 000 female condoms were sold<sup>19</sup> in various outlets.<sup>20</sup>

More than half of all the people living with HIV in Zimbabwe are women, however the condom distribution figure is not representative of this; it also shows that only 0.4% of the over 85 million condoms were freely distributed in 2004. Female condoms are an effective, female-initiated, method of HIV prevention. The distribution of condoms shows a bias towards male condoms and, as argued, the National Strategic Plan is, by implication, endorsing women's vulnerabilities by the failure to provide for female condoms. In addition, 68% of all government-distributed female condoms were sold in 2004. The 'sale' of female condoms, as compared to making condoms freely available, places women at an even further disadvantage, especially given the financially vulnerable position of women in Zimbabwe.

Furthermore, while a recent news article<sup>21</sup> puts the cost of female condoms at less than one US cent per condom, a

**...women are at an even greater risk of HIV infection, as a result of the prevailing violence and instability...**

recent call to three of the most widely distributed pharmacies in Zimbabwe, revealed that the female condom is selling at between \$0.50 and \$1.<sup>22</sup> Yet, according to the Bread for the World Institute,

*...the latest available national statistics show that 45 percent of the population is undernourished.*<sup>23</sup>

Recognising that in any economy in the world, poverty

**...more female condoms should be distributed freely, as is the case with male condoms...**

affects women the most, raises the question of how many women can indeed afford to buy a single female condom, when they can barely afford to buy food.

It appears that in this respect Zimbabwe is no different than the rest of the world. While acknowledged to be a highly effective prevention method, and currently the only female-initiated method of prevention of HIV and other STIs, only twenty-six million

female condoms were distributed in 2007, compared to some 12 billion male condoms.<sup>24</sup> What makes the situation in Zimbabwe particularly unique, however, is that, in a country with such high unemployment rates and growing poverty amongst women, one wonders how, in the face of the high per capita female condom distribution, who has access to female condoms.

#### **WHAT SHOULD A MORE MEANINGFUL RESPONSE FOR WOMEN LOOK LIKE?**

As Sippel [2008:6] notes,

*A high quality female condom programming is critical to increasing female condom demand and uptake.*

Sippel goes on to suggest that programmes needed to ensure that distribution of these condoms is creative and conformable to the potential consumers. The condoms are certainly on sale, but given the evidence, only people of a certain income bracket can afford them.

A more relevant response would be a situation where the government invests more into free and highly subsidised female condoms, in order to ensure that more women have access to condoms. In addition, an enabling environment needs to be in place, a situation where women are able to live without fear

of being evicted or forcibly moved; a situation where greater efforts are made towards the financial and economic stability of women. In addition, further research into usage and acceptance patterns is also required.

### CONCLUSION

**...we must ask what this praise of Zimbabwe's female condom distribution means for Zimbabwean women...**

In conclusion, while the condom distribution story in Zimbabwe is impressive, the socio-economic situation in the country, coupled with the challenges of women's access to

female condoms, the picture, as presented, does not seem to add up, as the majority of women are not represented. Already, the higher HIV prevalence amongst young women is proof of a more dire situation.

In a country of 12 million and an estimated HIV prevalence rate of 15,3%, with a consistently higher HIV prevalence amongst women, particularly married women – could the female condom distribution 'success' story simply be a good case at playing the numbers game?

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*Lydia Mavengere is the Assistant Editor  
at the AIDS Legal Network (ALN).  
For more information and/or comments,  
please contact her at project@aln.org.za.*

# Very important, yet complicated task...

## Sex workers' involvement in HIV prevention in Russia

*Practically, sex workers in Russia do not have any rights!*

*We can be robbed, raped, and murdered, and both the state and law enforcement authorities do not care about it in any way. 'You knew what you were doing!' – is the answer police will give to a sex worker asking for help. Sex work is criminalised; which speaks for itself...*

*In this article I will show how an HIV prevention project can involve sex workers and therefore, contribute to the self-determination of our society.*

**Irina Maslova**

### HIV PREVENTION MODELS

There are three models of HIV prevention projects amongst sex workers. The first model consists of compulsory screening and the registration of sex workers. Healthcare workers support this model and stipulate their position by the necessity of controlling the spread of STDs and the HIV epidemics. This approach, however, leads to the increasing stigmatisation of sex workers and their further isolation from the society, which makes them much more vulnerable to epidemics. The increasing social control over the community of sex workers may also lead to the increasing intensity of their work and rotation of clients; hence, perceived risks will be lower, while meanwhile real risks will increase.

The second model is based on the provision of available and adequate healthcare services for sex workers. This model reflects the view that healthcare workers should assess the needs of their clients adequately, and offer

services according to their clients' needs. Services which nobody use cannot be considered qualitative service, irrespective of their high technical standards, because these services do not meet their primary goal, which should be satisfying clients' needs. In this case, outreach work serves as a tool for bringing healthcare services to the client. This is achieved by gaining clients' trust at the initial stage of contact, and collecting information about clients' needs, which allows adapting services to the needs of clients more accurately.

The third model – the transformation of a sex worker into a central figure interested in strengthening her own health – presupposes a higher level of the development of outreach work. The major focus of this model lies in the management of the target groups' demands. The best results are reached, when sex workers are integrated into outreach projects, and working almost independently in the sex worker community.

And it is this last model, which is most effective and sustainable for HIV prevention programmes amongst sex workers.

**...takes quite a lot of  
time, energy and power  
– but gives a precious  
experience!...**

### WHY ARE SEX WORKERS INVOLVED AS 'EQUAL MEMBERS' IN THE PROJECT?

For most projects it is necessary to involve volunteers into their work; as we all understand that the project funds are limited. With increasing the numbers of volunteers, the projects' reach increases and thus, the target group is significantly higher.

The programme idea, 'equal to equal', is based on the concept that volunteers are recruited and trained to become 'equal members' of the project.

The involvement of sex workers as 'equal members' in the project also makes the programme very flexible, as it is designed to adapt to the changing needs of the community. After due preparations and training of sex worker volunteers, it is possible to involve them as co-trainers in educating both the target group and specialists. One of the results of involving sex workers as 'equal members' of the project team is that the quality and reliability of reports on condom use is increased, and descriptions of the situation amongst sex workers, and assessments on the quality of the project's services are more accurate. Also, the dissemination of information to the community happens much faster and in a more accessible way when sex worker volunteers are involved. In the context of sex workers' lack of legal recognition, it is easier for sex worker communities to stand up for their own rights, as the

participation of skilled volunteers from the community itself impacts greatly on the community's sense of responsibility and self-assessment.

Furthermore, the equal participation of sex workers in all stages of the project not only affects the quality of the project, but also ensures greater transparency of our programme in the target community. This approach also impacts on the sustainability of HIV prevention programmes, as the project can continue after funders have left.

### THE ISSUES OF MOTIVATION

An absolutely logical question to be raised here – 'Why and what for do sex workers cooperate with us as volunteers?' In order to answer this question let us first try and describe the profile of an average sex worker.

A woman, 24 to 28 years old, who is injecting drugs or has done so in the past, or is abusing alcohol. A mother with one or two children, who has a husband or sexual partner dependant on her. She has secondary school or secondary vocational education; she has most likely experienced violence in childhood; and has a low self-esteem. She is also a woman who is the subject of stigmatisation and self-discrimination. Very often sex workers do not have documents and/or medical

...a very important, yet  
complicated, task...

...aimed at self-realisation  
and active involvement in  
matters affecting  
the community of  
sex workers...

insurance; and their skills of socialising seem to be lost. BUT... with all of this; all sex workers are good psychologists – life has made them such! They know the relationships between men and women very well. They are very responsive to attention and have a sincere interest in their own destiny. Sex workers know how to find a way out of complicated and dangerous situations. They have the skills of effective communication and self-presentation, and often become ‘*counsellors*’ to their clients.

These are the strong features, which form the foundation for involving sex workers as volunteers and empowering them to participate as ‘*equal members*’ in HIV prevention work.

First, there are the human relations that are based on our sincere interest in every person. Every single woman is important to us – her destiny, her life, and her potential; which very often she is not even aware of. We are the first and the last people, who will see an individual and a woman in her.

And, as every other person, a sex worker has inner desires and needs (realised and unrealised). Whilst satisfying these desires and needs, we involve the representatives of the target group into the implementation of our projects and programmes.

Some of the expectations, expressed by sex worker volunteers, include:

- Greater self-consciousness of personal problem zones, as well as ways of solving these problems
- Expectations related to personal growth
- Expectations of gaining knowledge, such as receiving

information about HIV and HIV prevention, the legal aspects of sex work, and the international experience of organisations protecting the rights of sex workers

- Self-realisation and the possibilities of applying their own experiences in our programmes
- Communication skills, the skills of solving conflict situations successfully, leadership skills, and volunteering.

While satisfying personal needs and expectations a sex worker also realises her own role in the mission, aims and tasks of the organisation and its programmes.

The second stage of volunteer development focuses on building individual and collective responsibility for changing the situation in sex worker communities, concerning both the HIV-related situation and the self-determination of the community. In our experience, nothing increases the feeling of responsibility and personal significance more

than the implementation of programme ideas suggested by volunteers; as this reflects the real meaning of ‘*equal members*’ in the project.

There are two major questions which sex workers ask themselves: ‘*Why is it necessary for me personally to deal with improving the HIV-related situation?*’, and ‘*What can I personally do to make a difference?*’. These questions show, amongst other things, the realisation that sex workers’ involvement in HIV prevention programmes for sex workers is important. That is why support groups and organisations

...from being the project's client to becoming 'equal members' of the project's multi-disciplinary team...

of sex workers follow the motto/slogan: '*Nothing about us without us!*'.

And, thirdly, there are the achievement awards for completed work, which are of a material, as well as a non-material nature. Our volunteers very much appreciate theatre tickets and collective trips out of town, or trips to the skating-rink. And in our experience, additional stimuli and awards, bonuses and encouragements have helped to establish a very good reputation of the programme.

#### TYPES OF EDUCATION

At the very beginning stage of selecting volunteers from our target group, strong and confidential relationships are established. The long history of our organisation, Humanitarian Action, and our long-term outreach work experiences, which have always been on confidentiality, assists in establishing this relationship with our volunteers right from the beginning. Over the years, many of our volunteers have developed from being the project's client to becoming '*equal members*' of the project's multi-disciplinary team.

Training is a major focus of our work and the ongoing provision of training to our clients and partners very much assisted in the success of our programme. Some of the topics covered by the training include HIV and STI

**...a sex worker also realises her own role in the mission, aims and tasks of the organisation...**

prevention; drug addiction; leadership skills; communication skills; self-defence; counselling skills; and beauty school.

There is also a training entitled '*Sex workers are on the guard of the nation's health*'. This particular training, including its title, has been developed by sex workers themselves, and is designed to take place in new brothels, where they manage to gain entry, due to their acquaintances.

The different trainings may be a full one-day session (8 hours) or mini-training sessions (3-4 hours). But, judging by my own experience, whole day-long trainings are the most effective. The mentioned training sessions, as well as the individual work with sex workers, are aimed at self-realisation and active involvement in matters affecting the community of sex workers; as well as creating the feeling of a team. For this, we also devote attention to forming team spirit and team thinking.

It is very important to ensure that the '*equal members*' of the project do not experience '*burn-out*'. To prevent this from happening, group and individual supervision is provided, continuous feedback is given, and regular formal and informal meetings are held.

In addition to all of this, our experiences show that it is important to create a transparent system of selecting volunteers, reporting, and the criteria used to evaluate the outcome of the activities. There is also the possibility of entering into a contract

**...we involve the representatives of the target group into the implementation of our projects and programmes...**

with the 'equal members', so as to formalise their involvement in the project.

## RESULTS AND CONCLUSIONS

Motivating people to be involved in HIV prevention work in their own community is a very important, yet complicated, task. It is equally important to support the motivations of volunteers before and after the training sessions; to create conducive conditions for their further self-realisation, and to support them in fulfilling undertaken responsibilities. Creating possibilities for personal growth is as an important component of the programme as the involvement of volunteers itself, and these components would make no sense without each other. Nothing disappoints people united by the same idea more than non-fulfilment of undertaken responsibilities.

The work with 'equal members', including the support in creating strong support groups, is very laborious and takes quite

a lot of time, energy and power – but gives a precious experience!

Without any doubt the involvement of volunteers as 'equal members' in our project increases the

self-esteem of sex workers, teaches them to set new personal aims, and broadens their possibilities and choices. And there

**...perceived risks will be lower, while meanwhile real risks will increase...**

is always a chance to change one's own life and find a new job, which is usually the way that volunteers leave the project. On the one side, these changes bring satisfaction and joy, and on the other everything starts again from the beginning – it is what we call LIFE.

And in conclusion, I would like to tell a famous fable.

## ALL IS IN YOUR HANDS

*Once upon a time there lived a wise man in a town. And he knew the answers to all questions. But an envious man decided to deceive the wise man. He went to the field and caught a butterfly. Clutching it in his hand he thought: 'I will go to the wise man and ask if the butterfly is alive. If he answers yes, I will smash it and tell he is not right, and if he answers no, I will open my palm and the butterfly will fly away!'*

*So, he came up to the wise man and asked: 'Wise man, they say you know everything in the world so answer me, is the butterfly alive?'*

*And the wise man answered to this: 'All is in your hands!'*

*Irina Maslova is the Programme Coordinator at Humanitarian Action, based in St Petersburg, Russia.*

*For more information and/or comments, please contact her at [club.silver.rose@gmail.com](mailto:club.silver.rose@gmail.com).*

# WECARE+...

## Moving forward the Positive Women's Agenda, linking across Europe and Central Asia

**Alice Welbourn** introduces WECARE+ and the thinking behind it

It may seem strange to hear, but there has never been a formerly registered network of positive women reaching across this Northern continent, which is to be home to the next International AIDS Conference<sup>3</sup>. There was pioneering and courageous activism of some key European women living with HIV in the early days of HIV, through starting Positively Women in the UK and, after that, the International Community of Women living with HIV and AIDS<sup>4</sup>. Since then, however, there has been relatively little development of regional HIV activism, especially by and for positive women in Western Europe, compared with that of other corners of the world. In Eastern Europe and Central Asia there is ECUO – the East Europe and Central Asia Union of People living with HIV and AIDS<sup>5</sup>. And there is the Global Network of People living with HIV and AIDS Europe Region<sup>6</sup>. But neither of these groups to date has a specific European sub-grouping for women with HIV.

In 2005, Marijo Vazquez of Creación Positiva<sup>7</sup> in Spain and ICW, I and other colleagues in Europe, discussed the idea of setting up a network of positive women across Europe, to complement the great work of other regional positive women's networks. No doubt, others had had this idea before us. Until now, however, other priorities have always seemed more pressing. Finally though, with the pressing advent of the

Vienna Conference, we have decided that it is time to seize the opportunity and act now to rectify this.

What reasons are there for a lack of a European structure? We think there are multiple reasons. Language is one – there are so many different languages in Europe. Another is that relatively, women in Western Europe at least are, of course, much wealthier than on other continents. Thus, it is assumed that women face greater challenges elsewhere than in Europe. This is true to some degree. However, many studies have shown that quality of life is most affected not by absolute poverty but by *relative*

poverty<sup>8</sup>, in relation to others around you.

This means that many women, especially women who are single mothers, for instance, can feel socially excluded, because they are not able to take part in the kinds of normal social activities that others around them with children are able to afford. So by this scale, many women living with HIV are still very poor and disadvantaged, even in Western Europe. But because Europe is seen as a rich

continent, there is extremely little funding available to support positive women in Europe and most of our work has to be done on a voluntary basis – just as elsewhere.

A third reason is that treatment availability has, ironically, pushed HIV underground. People have assumed that because treatment is available, HIV is sorted out and that stigma would become history. Of course we all know that this is not the case, but it is hard to explain to others.

HIV in Europe is also a challenge, because the overall

**...we trust that we can  
redefine, recreate and  
sustain a more humane  
response to HIV...**

numbers of women with HIV are still low compared with elsewhere – so HIV is seen as a minor problem, not relevant to most people. Moreover, the majority of people with HIV in Europe are still gay men, and people are often amazed to hear how many women have the virus. Women with HIV in the region also come from many diverse backgrounds. There are probably women with HIV in Europe from all corners of the world. Furthermore, the increasing challenges of HIV transmitted through injecting drug use are particularly large in Eastern Europe, where there is still little scientific and human rights-based harm reduction provision. As a result, HIV understanding in Europe is limited, as it is seen as a ‘foreigner’ or a ‘gay’ or a ‘junky’ disease, associated with high levels of stigma to do with race, homophobia and other misunderstood health issues.

There are also increasing numbers of older women who acquire HIV from their long-term partners or, if divorced perhaps, after a holiday romance, discover that they are HIV

positive. They dare not speak out about their HIV status for fear of shame or ridicule, and also for fear that their children may no longer allow them to cuddle their grandchildren.

Some positive women who have been powerful activists in the past, have decided to move back into private life, in order to raise a family or start a new

**...the enormity of the challenges, which even the ‘developed’ world still needs to address...**

relationship, without being in the public eye. Given the stigma in Europe, this is entirely understandable and their rights to do this need to be respected. At the other end of the scale, younger positive women who are just starting their adult lives are fearful of being open about their status, because of the effect it might have on their ability to form relationships, have children or develop their careers.

For all these reasons, many women with HIV just want to get on with their lives, protect their children, keep their jobs and not speak out about their HIV status, because the risks of their disclosure are so huge. So ironically in many ways, HIV for women of all ages is still very hidden – and is also a huge problem for us in Europe, despite Europe calling itself the ‘developed’ world.

The Vienna Conference offers us therefore a rare opportunity to turn the spotlight of the world on what is happening in Europe, to raise awareness of European governments, professionals, the media and society to what is happening in their own region, to change attitudes, policies and practices towards women with HIV in Europe and Central Asia – and globally – and to reduce women’s and girls’ vulnerability to HIV in Europe.

In preparation for Vienna, a number of positive women activists from across Europe have decided to form ‘Women in Europe and Central Asia Region Plus’ – ‘WECARE+’ for short. This decision emerged from a side-meeting for positive women only, held during a larger landmark meeting of European agencies working on women and HIV, in Vienna, in October 2009.<sup>9</sup> We also resolved to seek funds to appoint a European Regional Coordinator, who would be an openly positive women, based somewhere within the region, most likely in the country of her origin, to work on advocacy issues across the region.

Of course in Europe and Central Asia, as elsewhere, positive women have been doing amazing things with virtually no resources.

As Sophie Dilmitis of World YWCA<sup>10</sup> reports:

*This meeting was an incredible experience to hear first hand what women are going through in Europe.... People from Austria set the scene in saying that there are around twelve to fifteen thousand people living with HIV in Austria and half of these live in Vienna – but there are no figures on women living with HIV in Vienna. The person who delivered the presentation has been living with HIV for 14 years and is the only positive woman who is open about her status in Vienna. People experience stigma and discrimination especially in the medical services. There are also not enough doctors to support all the positive people in Austria and they need more active people to fight for rights and address stigma and discrimination. ....*

*Women will come to a support group but will not disclose their HIV status. Women are mainly infected by heterosexual contact and through drug use. There are also issues in prisons and there is Hepatitis C and B co-infection. Another issue is that sex workers have to register to do this work and they then have to have a weekly check up. If they are diagnosed HIV positive they lose their licence to work and then they are not protected at all by laws that protect sex workers and they still continue to engage in sex work. Also as women with HIV are aging, the health system is not geared to deal with this in Austria. An organization was founded last year for women and HIV in Austria and unites all the experience of women living with HIV and people from the pharmaceutical*

*industry and concerned people who want to get involved. They have already had a national meeting of women to understand the situation of women as people seem to be working in silos and are not sharing information. This group supports women irrespective of their HIV status.*

Vienna is one of the world's most rich and cultured cities. It was also host to the UN World Conference on Human Rights in 1993. As Charlotte Bunch<sup>11</sup>, Founding Director and

Senior Scholar at the Center for Women's Global Leadership, explains:

**...they dare not speak out about their HIV status for fear of shame or ridicule...**

**Human Rights** – *Women were primarily seen as part of the social and economic work of the*

*UN, and women's rights were only rarely addressed in the human rights arena before the 1990s. The change in this perception came most forcefully at the UN World Conference on Human Rights in Vienna in 1993. With the cold war over and the issue of rape in war gaining media coverage in Bosnia, women seized the opportunity to demand attention to women's rights as human rights. They organized across the North-South divide and in all the regional preparatory processes to ensure that the Vienna Declaration and Programme of Action included a strong affirmation of the rights of women as universal human rights, and in particular for the recognition that all forms of violence against women are a violation of human rights.*

*One of the specific demands in Vienna was for a Special Rapporteur on Violence Against Women, its Causes and Consequences to report to the Commission on Human Rights (CHR) in Geneva. This Rapporteur was appointed in 1994, and her annual reports have elaborated human rights standards on VAW and outlined government's responsibilities to abide by those standards in concrete policy terms, following the parameters outlined in the UN Declaration on VAW. Another call from Vienna was for gender integration into all the work of the human rights machinery – the subject of annual resolutions at the CHR since 1994 and now at the Human Rights Council. The Office of the UN High Commissioner for Human Rights (OHCHR) has included a mandate for gender integration from its inception, and a growing number of human rights treaty bodies and special procedures have given attention to the gendered aspects of their mandates, including the Committee on Torture and on Racial Discrimination.*

*A number of gender related human rights issues have raised important but difficult debates and controversies. The discussion of sexual rights is implicit in the Vienna, Cairo, and Beijing World Conference documents, where reference is made to the right to control over one's sexuality...*

So it is hard to hear about the situation

**...people are often amazed to hear how many women have the virus...**

**...HIV is seen as a minor problem, not relevant to most people...**

facing women with HIV in Austria now, 17 years on from this World Conference, especially as it prepares to host the next International AIDS Conference.

By contrast, the former Soviet block countries experience immense poverty. As Silvia Petretti<sup>12</sup> reported:

*...the reports from Eastern Europe were quite chilling. The women from Russia were among the youngest in our group, mainly in their early twenties, but nevertheless, you could see really motivated activists. Russia has one of the fastest growing and largest HIV epidemics in Europe. The official numbers from the government are low, a few hundred thousands, however WHO estimates there are over 1,000,000 people living with HIV and 38% of those are women. The women at our meeting highlighted that even if heterosexual transmission and intravenous drug use are the main routes of transmission, shockingly, some women also [acquire HIV] in hospitals, because of lack of universal precautions. They also talked about the immense lack of resources, especially for women in prison, who don't have absolutely any access either to prevention or treatment.*

*Stigma and discrimination are rampant in Russia, and among the general population there is still the false perception that HIV only affects drug users and 'prostitutes'. If the women are drug users and want to access HIV treatment they need to register as drug users and this puts them at risk to lose custody of their children. Therefore women often get*

*really sick and die, because trying to access medication could lead to being separated from their children.*

Wezi Thamm from the UK spoke of the 'double whammy' of being an African woman living with HIV. There are huge

trust and confidentiality fears for African women who are also dealing with being far from home, often having lost family members through conflict or AIDS, facing racism and many other related issues. It often seems

hard to get anyone to take these stresses seriously. In the UK, 78% of women living with HIV are from high prevalence countries. Moreover in the UK, there are women with HIV and their children held in asylum centres without access to ARVs.

In the middle of Europe, as described by Silvia Petretti:

*Something that was really shocking for me is what has been happening in Albania. I know that it is one of the poorest countries in the EU, but it is also really close to Italy, just a few miles across the water. I couldn't believe the story one woman [Olimbi<sup>13</sup>] told. A mother of 4 children, 3 of them HIV+. They all got diagnosed after her husband (who had never disclosed to her) died of AIDS in 2004. Two of the children were also really sick, and nearly died because they couldn't get treatment. I just cannot believe that this was happening a few miles from Italy*

*in 2004. This woman fought like a lioness for her and her children's rights to treatment, and for once this story has a happy ending and they got their meds in the end and survived. She is now one of the heads of the movement for the rights of PLHIV in Albania.*

Other issues faced by positive women in Europe and Central Asia echo those in many other parts of the world. These include sexual and reproductive rights issues; feared and real physical, sexual and psychological violence from partners, especially on disclosure; threats of criminalisation; fear around disclosing to new partners and of starting new relationships; young positive women's issues (about which there is barely any information); issues facing women in prison; LGBT issues; and chronic depression.

Many more stories were told – too many to include here, but we hope that this short article has given a flavour of the enormity of the challenges, which even the 'developed' world still needs to address in its attitudes and practices towards women with HIV. This is why WECARE+ has been set up.

Finally, our initiative in Europe and Central Asia is designed, we hope, not only to benefit all women and girls within our region, but also to benefit other women and girls around the world – and ultimately all with whom they relate. Since the European Union is the single largest donor to world aid after the US Government, there is much that we seek to do to hold all the Western and Eastern European states and the European Union to account for both their domestic track records and their international donor commitments to the rights of women worldwide. Although there is much to admire and appreciate

**...it is hard to explain to others...**

**...there has been relatively little development of regional HIV activism, especially by and for positive women in Western Europe...**

about Western governments' practices, there is also much room for improvement.

The strapline for the Vienna International AIDS Conference is '*Rights Here, Right Now*'. We hope and trust that the Vienna AIDS Conference will offer us all the opportunity to reassert the human rights of women as a core part of universal human rights, as declared in Vienna back in 1993. We hope and trust that this International AIDS Conference will enable a diverse range of civil society across our region to engage with donors and policy makers alike. Together we trust that we can redefine, recreate and *sustain* a more humane response to HIV, for the benefit of us all.

#### FOOTNOTES:

1. With thanks to Sophie Dilmitis, Silvia Petretti and Wezi Thamm for their contributions to this article.
2. Alice Welbourn is supporting women across Europe and Central Asia to launch WECARE+.
3. [[www.aids2010.org/](http://www.aids2010.org/)]
4. [[www.icw.org/about-ICW](http://www.icw.org/about-ICW)]
5. [[www.ecuo.org](http://www.ecuo.org)]
6. The GNP Europe region is yet to have its own website. [[www.gnpplus.net/content/view/1550/125/](http://www.gnpplus.net/content/view/1550/125/)]
7. [<http://creacionpositiva.net/>]
8. See, for instance, further discussion and explanation of these terms at [[www.poverty.org.uk/summary/social%20exclusion.shtml](http://www.poverty.org.uk/summary/social%20exclusion.shtml)] and at [[http://news.bbc.co.uk/2/hi/uk\\_news/6361349.stm](http://news.bbc.co.uk/2/hi/uk_news/6361349.stm)]
9. At this side meeting, we decided to register WECARE+ centrally in the region – in Germany. We also decided to form an interim initial voluntary board of trustees for this group from right across the region, of whom a minimum of 80% would be openly HIV positive. (This initial interim board will be replaced by a fully elected board after an initial year.)
10. [[www.worldywca.org/](http://www.worldywca.org/)]
11. Bunch, C. 2009: 'Women's Rights and Gender at the United Nations: The Case for a New Gender Equality Architecture'. (to be published in Vereinte Nationen: German Review on the United Nations, 2009)
12. [<http://hivpolicyspeakup.wordpress.com/2009/11/13/women-in-europe-vienna-2010-and-beyond/>]
13. To read more about Olimbi and her work, see [www.sophiaforum.net/index.php/News/House\\_of\\_Commons](http://www.sophiaforum.net/index.php/News/House_of_Commons).

*Alice Welbourn is a UK-based activist, writer, networker and trainer, who was diagnosed with HIV in 1992. She currently serves as the Chair of the Sophia Forum – the UK Chapter of the Global Coalition on Women and AIDS and is Founder and Director of the Salamander Trust.*

*For more information and/or comments, please contact her at [alice@salamandertrust.net](mailto:alice@salamandertrust.net).*

## Women in Europe and Central Asia Region Plus – WECARE+

*We welcome all of you living with HIV in Europe and Central Asia to join us.*

*We have started a closed listserv for HIV positive women who live in Europe and Central Asia only. If you fit these criteria and would like to join this listserv, you are most welcome.*

*Please contact [wecareplus@yahoo.com](mailto:wecareplus@yahoo.com).*

*We also have an open, multi-language website for anyone to visit and share information at [www.womeneurope.net](http://www.womeneurope.net)*

*PS: WECARE+ is urgently in need of funding to develop our activities across Europe.*

*If you are able to support us, we would be delighted to hear from you.*

# In conversation with Milly Katana<sup>1</sup>

**Milly Katana is a Ugandan public health professional with strong experience and commitment to expanding the role of people living with HIV and AIDS in prevention, care, support and treatment programmes. Milly is a founder of a health rights action group in Uganda and Country Director for the International HIV and AIDS Alliance in Uganda.**

**TC: When did you become an AIDS activist?**

**MK:** I got involved in AIDS work in 1995, when I tested HIV positive, and it's then that I linked up with an upcoming network of people living with HIV in my country. By then it was small, the stigma was intense and very few people who had a bit of social standing were willing to come out and associate with people living with HIV. I got a job with a research institute, which was working on AIDS issues, and that's when I realised that the problem of HIV was indeed very big in my country. I was encouraged by my friends to do something; and in this Network we had very humble people, because the more educated were not joining.

At the time, we had this army officer who was organising us; people would call him privately or go to his office, but they would never openly associate with the organisation, and we needed some things done by the organisation, mobilising, and getting more members, and reaching out to our friends – so that's how I got involved. I said well, stigma put aside, let me join and offer something, my skill; by then I was primarily

working on financial issues; budgeting, proposal writing, that's what I could offer.

**TC: What was it like for women in the AIDS response at that time?**

**MK:** It was very difficult, and still continues to be very difficult. But because of the fact that HIV mostly affects women, women were more represented in the networks and associations of people living with HIV. Also because of our better healthcare seeking behaviour, and openness in talking about issues that affect us; so the pain that is associated with HIV is a bit shared between people who have the same problem, unlike our colleagues, the men who suffer alone most of the time. It was difficult, but women were more willing to come out and engage with us.

**TC: What do you think is the most pressing issue for women then and for women now?**

**MK:** The most pressing issue for women then was the issue of disclosure to family members, especially for those who were in relationships. Disclosing to their

spouses and partners, and relatives, of either their late husbands or spouses, which often meant that once they did disclose, they would be asked to leave their homes. And those who had children even faced a double tragedy of having to deal with not only the illness and suffering associated with it, but also coping with bringing up children. Yet, they have been asked to leave, sometimes in a violent manner, from their husbands' properties.

**TC: What do you think is the most pressing issue now; is it the same or has it changed?**

**MK:** A few things are changing now, with access to treatment, and the more accommodation that society has of people living with HIV, but this is not 100%. I cannot say that for every woman life is easy. There are some of our friends who still get stories of women who are being thrown out by their late husbands' families, once they learn that the husband has died of AIDS, and this woman has children.

But also we are faced with issues of employment for those who are living with HIV. There is a small undercover stigma for employing women and other people that are living with HIV, because most of the work for women is in the service industry. Most of them may work in hotels for instance or the food industry and employers are not willing to take on individuals living with HIV. They will never say that it is because of one's HIV status, but they will make life very difficult, to the

extent that one just gives up. In schools for instance, those who are teachers, students or pupils, can scorn them. A teacher may walk into a class and find that kids have drawn cartoons that mention AIDS, or even call them names and things like that. So there are many problems for sure.

**TC: What are the issues that you have been most passionate about?**

**MK:** For purposes of survival, I have been most passionate about issues of access to treatment, because without treatment, many of us would have been dead. In fact many of the friends whom I first worked with in the Network are now long gone, because we didn't have treatment; not only ARVs, but also for the major opportunistic infections. We lost many of our friends to ...meningitis and tuberculosis, which is still a problem until now. But things are getting a little better, though we are moving in cycles with the corruption in most of our African countries. The funding flow is interrupted because of the misuse of funds and therefore sustainability of care is a bit of a challenge.

**TC: If you had one wish...?**

**MK:** If I had one wish, of course there are many wishes, I wish the numbers of new people who get infected is drastically brought to a halt, because that would mean that the burden of care for those who are living with HIV would be reduced as well. That is my biggest wish.

**TC: Is there any hope of that?**

**MK:** I think there is some hope; with some ground being covered on matters of vaccine development, and matters of prevention of mother to child transmission. I hope in some years to come, things will be different. If we had not been optimistic, even on the treatment front, we would not be where we are. So we need to continue having hope.

**TC: What is your biggest disappointment?**

**MK:** My biggest disappointment is the way developing countries handle the issue of investment in our healthcare systems, because I always say that HIV is a blessing in disguise. It has given us an opportunity to seek for a lot of foreign assistance to invest into our healthcare delivery systems. If we put this assistance to good use, it would tremendously revamp the way we look after our sick, not only those who are sick from AIDS, but also those who are sick from all sorts of other infections and non-infectious diseases. But the money that we receive from the generous international community has not been put to good use. This is my biggest disappointment.

**TC: What is your biggest achievement?**

**MK:** The biggest achievement has been the solidarity that the world has shown as far as AIDS is concerned. Also in the history of public health, I think there is not any one disease which has garnered as much support as HIV has. And for me, this is something we need to be very proud of.

**TC: Anything else?**

**MK:** As far as my wish list is concerned, it is also for the international community to continuously invest into science and such for newer and better treatment, and also for remedies which would bring the epidemic to a complete stop. We have overcome most of the other diseases that humanity has suffered in the past; and if we get a vaccine for instance, life would be different.

**FOOTNOTE**

1. The interview was conducted by Tyler Crone (TC) of the ATHENA Network on 06 February 2010.



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**Editors:** Johanna Kehler ([jkahn@mweb.co.za](mailto:jkahn@mweb.co.za)), E. Tyler Crone ([tyler.crone@gmail.com](mailto:tyler.crone@gmail.com)) • **DTP Design:** Melissa Smith ([melissas1@telkomsa.net](mailto:melissas1@telkomsa.net)) • **Printing:** FA Print  
Tel: +27 21 447 8435 • Fax: +27 21 447 9946 • E-mail: [alnpt@aln.org.za](mailto:alnpt@aln.org.za) • Website: [www.aln.org.za](http://www.aln.org.za)