Special Edition incorporating

aLQ

AIDS LEGAL NETWORK

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Mujeres Adelante

Daily newsletter on women's rights and HIV – Mexico City 2008

Luisa Orza

Hot topics in Mexico

Among ICW women, and our friends and allies, the main topics which provoked the most controversy or interest included sex work, medical male circumcision, criminalisation of HIV transmission, the ICW litigation project focusing on sterilisation of HIV positive women, violence against women, and how to tackle the poverty so many women live in. Many of these areas were examined in the Women's Networking Zone (WNZ) and The Positive Space sessions, as well as during events in the main conference. What follows are reports and deliberations on some of these topics.

CRIMINALISATION WILL HARM, NOT HELP – HOT TOPIC I[1]

Criminalisation was one of the emerging hot topics that seemed to be on everyone's lips at the Mexico City 2008 AIDS Conference, and ICW was among the leading voices on this subject, through a consultation during Living 2008, sessions in the Global Village, satellites and a poster presentation on the issue. ICW also supported Alice Welbourn's presentation on criminalisation in the main conference. To reward us for our hard work, our concerns were echoed – in the final day's plenary session – by openly HIV positive and gay South African judge Edwin Cameron. Criminalisation of HIV transmission is on the rise, as countries either adopt laws, which specifically criminalise the transmission of HIV, or apply other criminal laws to HIV transmission. This trend has serious implications for all people living with HIV, and some particular concerns for women and girls.

First, criminalisation increases stigma against HIV positive people, and is likely to discourage people from testing and learning their HIV status. This then, has an impact on people's ability to access treatment, care and support services, and

In this issue:

on the effectiveness of prevention programmes. Criminalisation laws are often unclear, and therefore, subject to interpretation by courts. This also raises questions about how marginalised groups are treated by the law. Legal uncertainties may leave already marginalised – or in some cases criminalised – groups, such as sex workers and intravenous drug users, vulnerable to abuse by courts. For women, a major concern is the potential criminalisation of mother-to-child-transmission of HIV in poor and isolated areas, where women have no access to prevention of mother-to-child transmission (PMTCT) services.

Second, women are often the first person in a household to learn of their HIV status through routine or ante-natal testing, which leaves women open to blame from partners, who have yet to test, and vulnerable to violence. Further, men often have greater access to legal services and legal literacy, which could skew the proportion of cases brought against women, even in situations where it is impossible to '*prove*' who transmitted the virus to whom. It is also unclear how the gendered dynamics of sex will play out in the courtroom. Will judges and juries take into account the difficulties some women face in negotiating condom use? And in countries, where marital rape is not acknowledged, could '*consent*' be used as a defence by husbands who have forced their wives to have sex with them?

A rights-based approach to the AIDS pandemic has gained a lot of momentum over the last decade, yet the move towards criminalisation does nothing to support this. On the contrary, criminalisation places often hard won rights of HIV positive women and men in jeopardy and, as a result, threatens an increase in stigma and discrimination.

MALE CIRCUMCISION – HOT TOPIC II

Although there was plenty of enthusiasm around plans to roll out medical male circumcision projects in Africa, women including HIV positive women, were divided. ICW's position is to be wary. The data from existing research can be interpreted in different ways, and the implementation of the programmes may be much more difficult to achieve than is being suggested. Women, including HIV positive women, raised other objections. ICW members and others reported newly circumcised men happily sharing the news that they can now have sex without using condoms. Other members from cultures, whose men are already routinely circumcised, pointed out that this had not necessarily meant that significantly lower numbers of men were contracting HIV in their communities. Another ICW member remarked that looking after newly circumcised men would present yet another burden of care for women. This brought to mind an issue raised in ICW before, namely the feminisation of blame. For instance, as women are often the first to be diagnosed in a family, via routine or antenatal HIV testing, they could be more likely to be blamed. In these circumstances, if their partners are circumcised, these women could end up taking the blame. In all the discussions in the WNZ, women agreed that male circumcision should never take the place of other ways of preventing HIV transmission, whether that was through safer sex campaigns, achieving women's human rights, the alleviation of poverty, or supporting communities.

...criminalisation ...seemed to be on everyone's lips...

GENDER, WOMEN AND VIOLENCE – HOT TOPIC III

Gender-based violence (GBV), or violence against women (VAW) attracted a lot of attention in discussions, often focusing on transmission of the HI virus. ICW worked hard to bring already HIV positive women's experiences of violence into the picture. One area which came up was how the words '*gender-based violence*' are increasingly being used in place of '*violence against women*' to describe a broad range of acts of violence that women experience. In one session in the WNZ, women tried to settle on when and where it was appropriate to use the word '*woman*', and when '*gender*'. Some ICW members and women from other networks reported that their members did not always know what '*gender*' meant. One woman said that gender was a way of understanding the relationship between men and women. To understand violence, one had to understand that relationship. Another suggested that '*gender*' made it possible to bring in the experiences of transgendered, and intersex people, as well as lesbians and gays. She said, '*We can't just talk about men and women anymore*'. An ICW staff member said that in her experience in large NGOs and other global organisations, if one wanted to be specific about HIV positive women's needs, one had to use the word '*women*'. Otherwise women and their specific experiences can be lost underneath the catchall word '*gender*'. Most women seemed to agree that however one uses the word, it is not '*gender*' that carries out violence against women. It is real people, most often men, who beat, bully, or bloody women.

In the end, gender is informed by the influences of all the other forces at work in our lives, including class, race, sexuality and geography. But it is people, real people, who sweat, cry out in pain and joy, and go about their ordinary lives day by day. As HIV positive women we have to be specific about exactly who we mean when we talk about gender.

ICW LITIGATION PROJECT IN NAMIBIA – HOT TOPIC IV

HIV Positive Women Against Forced or Coerced Sterilisation

...Women were sterilised without their knowledge during other procedures, such as caesareans...

Editorial…

> *…Women already have the capacity. For me, what is lacking is broadening the notion of inclusion, because most of our contributions are not well valued. It is necessary for institutions, organisations, networks, the UN system, or other networks of positive and non-positive members to redefine what we think participation is, and how people can participate in very many different ways*. [Mari Jo Vazquez, 2008]

This special edition of the ***ALQ*** is looking at women's rights and HIV. The various articles, contributions and comments are a reflection of existing and emerging '*hot issues*', debates and dialogues, as well as of the '*left out*' topics and continuing '*invisibilities*' – as transpired at the recent 2008 International AIDS Conference in Mexico City. This edition raises many questions, including as to whether or not women's rights and realities are adequately reflected in, and responded to, in the proceedings of international AIDS conferences; whether or not the realities and needs of local women are represented at the conference; whether or not '*marginalised*' groups and topics are moving towards the mainstream, or are remaining at the margins of research, debates and dialogues; whether or not human rights are indeed at the centre of global, regional and national responses to HIV and AIDS; and whether or not women's realities and needs are '*visible*', and women's voices are '*heard*'.

This issue is a **Special Edition** in many ways. It is special because of the variety of contributions, ranging from articles and reflections to feedbacks and comments about women's rights and HIV, as to the extent to which the topic was present, and presented, during the Mexico Conference. It is also a Special Edition, as this ***ALQ*** has been jointly produced by the ATHENA Network and the AIDS Legal Network – and hence, this edition has two editors: Tyler Crone and Johanna Kehler. And last, but not least, this is a Special Edition as it is a naturally grown amalgamation between the ***Mujeres Adelante*** – the daily newsletter on women's rights and HIV, published during the 2008 AIDS Conference – and the ***ALQ***.

Looking back at the recent International AIDS Conference in Mexico City, it is striking to realise how much remains the same, even as the global AIDS response changes.

For the 2002 International AIDS Conference, an ad-hoc global alliance, which Tyler was part of, collaborated with local women living with HIV in Barcelona, with two central goals. One was to make the International AIDS Conference accessible to the local community and in so doing, create mechanisms by which research, advocacy, and community were in the position to meet. The second was to mobilise around a '*gender agenda*' and thus, place women's rights and gender equality at the heart of the AIDS response. HIV positive women, feminists, service providers, and researchers, among others (with all of us wearing multiple hats) came together under two umbrellas – that of '*Women at Barcelona*', for our work to organise around gender and human rights at the conference, and that of '*Mujeres Adelante*', for our collaboration with a local organisation of women living with HIV to build a parallel conference embedded in the Barcelona community that would be free and open to the public.

At a recent ICW advocacy-training project with young Namibian HIV positive women it came out that some of the participants had been sterilised, without their informed consent. Alarmed, ICW activists, including the young women, undertook a series of focus groups and interviews, which substantiated the young women's experiences of sterilisations by hospital staff.

So far, this ongoing research has discovered that out of the 230 HIV positive women, who participated in the research, 40 had been subjected to forced or coerced sterilisation. Thirteen cases have been taken up for possible litigation by the Legal Aid Centre (LAC) in Namibia and all 40 cases have been presented to the Deputy Minister of Health and Social Services. In addition, at least two of the women, represented by LAC, have filed cases before the High Court alleging violations of their right to life, human dignity, equality and the right to be free from cruel, inhuman and degrading treatment.

How were women forced or coerced?

- In many cases, informed consent was not adequately obtained from the women
- Consent was obtained under duress or pressure
- Consent was invalid, because the women were not informed of the content of the document they signed
- Medical personnel failed to provide full and accurate information about the sterilisation procedure
- Women were asked to sign forms, while they were in labour, or on their way to the operating theatre
- Women were told or given the impression that in order to obtain other medical procedures, such as an abortion or caesarean section or even medical help to give birth, they would have to consent to sterilisation.

In all cases, the medical personnel failed to provide women with a full description of the nature of the procedure, its effects, consequences and risks. No one informed the women of the irreversible nature of sterilisation, or provided them with information on alternative forms of birth control and family planning. ICW continues to engage in research and advocacy with partner organisations to end the forced and coerced sterilisation of women living with HIV.

...Unfortunately, some of the women also experienced discriminatory treatment. In one case, nurses refused to touch the patient and made disparaging remarks about her...

Young Namibian Women Speak out

Esther Sheehama and **Veronica Kalambi** are both young positive Namibian women, who are working on ICW's litigation project. Esther now sits on the National Council HIV Committee in Namibia. Both attended AIDS 2008 and both made presentations in the main conference, the WNZ and The Positive Space. Esther and Veronica made a strong impact with their articulate and confident talks, which gave clear information, framed by personal testimonies.

...women agreed that male circumcision should never take the place of other ways of preventing HIV transmission...

...Veronica and I presented the Namibian Litigations research to a large session in the WNZ. Many women and men came to listen and give their views on forced sterilisation. It's a big issue for me and most women in Namibia, because we are not allowed to speak out against the injustice that happened to us. Now, with the ICW project and mentoring from Jeni Gatsi, we are fighting for our rights. Although we have a national Charter, which seeks to tackle discrimination against HIV positive people, the reality is that HIV positive women are not treated equally to other women. We want to know what the community is doing about it? What is the church's action on the issue and what are HIV negative women doing? We want doctors, who do forced sterilisations to be accountable.

[Esther Sheehama]

...I presented on the project at the only all-positive panel in the main conference on the sexual and reproductive health rights of HIV positive women and men. When I got home after the conference, many women asked me when we will go to their regions to do the research on their experiences of sterilisation. I will make sure I use the skills I got from AIDS 2008 and make a difference for many old and young HIV positive women. I learned how to set up networks in an ICW session and how to help existing ones become even stronger, in order to uplift our members and empower women to stand up on their own.

[Veronica Kalambi]

FOOTNOTE:

1. Thanks to Aziza Ahmad for the material in this report.

Luisa is the Monitoring and Evaluation Officer of ICW.

Mujeres Adelante is the name we choose to carry forward for our newsletter on women's rights and HIV at the most recent International AIDS Conference in Mexico City – and it manifests a spirit that we seek to embrace. ***Mujeres Adelante*** – as the parallel community forum at the 2002 International AIDS Conference in Barcelona, as a newsletter at the 2008 International AIDS Conference, and as this special issue of the ***ALQ*** – manifests the desire of diverse stakeholders in the AIDS response to create a shared voice and vision around gender equality and women's rights; to bridge movements; to link sectors; and to create channels through which local and global are meeting, as well as the passion of women from around the world to interpret, own, and advance a rights-based response to HIV and AIDS.

In the following pages, we have attempted to capture pieces of the conversation that transpired at the recent International AIDS Conference in Mexico City and hence, take a snapshot of the state of women's rights in the response to HIV and AIDS. Further, we have attempted to offer a gendered analysis of who was speaking and what was said. It is our hope that this special issue of the ***ALQ*** will manifest the spirit and intent of ***Mujeres Adelante*** – *women moving forward* – and will serve as a portrait of where we have come from, and how much more distance we have yet to go in advancing gender equity and human rights in the global response to HIV and AIDS.

This special issue explores the implications of male circumcision as an HIV prevention tool for women and raises critical issues, such as how male circumcision could reinforce the stigmatisation of women living with HIV as '*vectors of disease*', and could undermine important gains in negotiating condom use, if male circumcision is viewed as a '*natural condom*', or an alternative to a vaccine. The various discussions pertaining to male circumcision raised the question as to why the global community is investing so heavily in male circumcision for HIV prevention, where HIV is disproportionately impacting women, and when the direct benefit of HIV prevention is only accrued by men. More than anything, the debate around male circumcision highlighted three essential points – 1) the need to engage women in HIV prevention research; 2) the need to build stronger links between research and community; and 3) the need for a broader array of HIV prevention methods that work for women and men.

Gender-based violence was another focal point at the recent International AIDS Conference in Mexico City. Anand Grover, the newly appointed Special Rapporteur on the Right to Health, stated:

> *…'so-called' normal women are being subjected to violence and that is not talked about. It is not an issue that is considered to be worthy to be talked about in the HIV world. That is a tragedy because HIV is closely linked to violence as is health. And if a woman becomes HIV-positive more violence ensues, which I think, the movement has to take up.*

And while gender-based violence was a focal point for multiple sessions at the International AIDS Conference, gender-based violence remains largely unexamined, as a significant driver and consequence of HIV infection, in the mainstream discourse. It is our strong belief that gender-based violence becomes increasingly recognised as an issue that deserves specific policies, programmes, and budget lines, so as

Ida Susser, Zena Stein and Marion Stevens

In Focus...

Young woman's voice heard for the first time…

Elisabet Fadul, a youth activist from the Dominican Republic became the first young woman to address the plenary sessions, since the start of the International AIDS Conferences.

She noted that of all HIV infections, 40% are among the youth – HIV is increasingly young, significantly female, and increasingly marginalised, and that below 50% of the goals set for access and prevention have been met. Referring to key messages developed by the Mexico Youth Force, a wide ranging coalition of groups, she articulated the call for:

- **Rights:** We have the right to comprehensive, accurate information, and service to protect our sexual health;
- **Respect**: for our realities, our experiences and our contributions;
- **Responsibilit**y: together, we must create an environment, where we have power over the decisions that affect our health and lives; and
- **Resources**: we need training, mentorship, funding and opportunities.

She also called for the '*implementation of rhetoric*', making governments accountable, and for greater investment in youth capacity. In referring to the inconsistent messaging towards young people, she gave the example that at

> *...age 18 we are able to fight in the military, but we cannot access contraception.*

This has been, because policy is informed by theological beliefs and is not evidenced-based. And we have not participated in the development of that curriculum.

She noted that the Caribbean governmental meeting has adopted evidenced-based sexual health in informing policy and services and added '*We expect to be at the table with you*'.

Jaime Sepulveda from the Gates Foundation called for a quantification of the effects of HIV prevention globally. He advocated for combination prevention strategies to accompany combination therapy and increased funds for a full range of prevention options. He affirmed that HIV prevention was not only cost-effective, but cost-saving. He noted the need to address the integration of HIV and AIDS and family planning and to, in particular, address the need of unintended pregnancy. In answering a question on the continuum of care, he noted, that

> *...we cannot treat our way out of the epidemic, we need combination prevention strategies.*

Alex Coutinho from Uganda noted the achievements of a million people on treatment, yet noted that 69% of those who should be on treatment are not on treatment. He noted the need to keep parents healthy, and to treatment as a strategy to deal with orphans. He claimed that treatment had already saved 200,000 from orphanhood, and pointed out, that of all the alternatives for raising children we know that, parents (we might say mothers) are the best.

In spite of the great advance in HIV treatment, new infections significantly outpace the numbers of people started on ART by a ratio of 5 to 2 (2.5 million new HIV infections, in comparison to 1 million on treatment).

More women than men globally are starting treatment, but only 12% of women have been assessed for their own treatment needs during pregnancy. Even this small percentage is a significant increase over the last two years.

He also noted that the number of infected babies born to HIV positive mothers has been greatly reduced by prevention from mother-to-child transmission of HIV (PMTCT). Mothers receiving PMTCT, which was only 10% in 2004, is 33% in 2007.

to be in the position to effectively address the gendered nature of HIV risks and vulnerabilities.

Reproductive choice – cornerstone of ATHENA's work – remains contested terrain, as HIV positive women claim a right to safe, healthy motherhood, while at the same time, coercive practices, such as the forced sterilisation of positive women in Namibia, and legislative trends to criminalise mother-to-child transmission of HIV, continue. The dialogue and debate in Mexico City reached new levels. Breastfeeding, safe and legal abortion, access to contraception, and the fertility desires of women living with HIV took the stage in multiple sessions. Thoughtful research, and behind the scenes advocacy, brought forward important discussions that had never before taken space at an International AIDS Conference. Among numerous conference delegates and community members there was great eagerness to learn more, and to engage, the entirety of reproductive choice in all of its complexity. A poster discussion on abortion, breastfeeding, and prevention of vertical transmission, among other topics – co-chaired by Tyler – was filled such that there was not an empty seat or a space to squeeze against the wall. A telling moment was when a physician from Chicago sought to find guidance and documentation of best practice on how to support her HIV positive women clients' to conceive and carry successful pregnancies – materials that have to date not been central, nor welcome in the AIDS response. If people were voting with their feet, the demand for more research – discussion – and debate around reproductive choice certainly was loud and clear.

The last point to be made here is about realising the spirit of ***Mujeres Adelante*** through this special edition of the ***ALQ***, and the creation of inclusive spaces, where diverse stakeholders can engage and contested issues can be interrogated. This special edition includes notable critiques around the resounding absence of attention to the particularities of lesbian women's experience at the nexus of women's rights and HIV, even as lesbian women are disproportionately affected in specific settings and are leaders in the field. This issue also includes indigenous women speaking with their own voice – and celebrates the innovation of women at the frontlines of the response in different places with distinct backgrounds, but with similar visions for justice and equality.

Even more, ***Mujeres Adelante*** is about finding ways for all of us, who are committed to advancing women's rights and gender equity, to meet – whether or not our work is focused on the local communities where we reside, or on transforming UN institutions and holding them to account. ***Mujeres Adelante*** is about building new and stronger alliances between the margins and the center – and about making visible what is all too frequently overlooked and giving voice to what is all too frequently silenced. And as we chanted at the 2002 International AIDS Conference, as we marched into the closing programme to protest the lack of space and lack of attention afforded to women and girls, '*Mujeres adelante estamos aqui!*'.

Johanna Kehler & Tyler Crone, October 2008

At the same time, he called for greater efforts to address violence against women and sex workers. In addressing medical male circumcision, he noted the limitations of the three research trials, which has lacked community-based studies, which can indicate how this possible strategy might have a population effect. Currently, we do not know, and have not seen, the results of the randomized clinical trials (RCTs) on a population. In addressing messaging, he noted the confusing negative messages and suggested that messaging should capture '*how to have sex, have fun and keep safe*'.

In commenting on the empowerment of women, he noted that it was often just addressing education and economic issues – but not sexual empowerment. Urbanised women have one level of empowerment missing – that of sexual empowerment. Women need this, and to have a continuum of sexual and reproductive health.

In answering a question about deporting illegal immigrants from Europe, he said that there is so little opportunity for treatment in Uganda that they should keep people in the UK on treatment, as part of their contribution of the global scale up of treatment.

And in reference to research he noted that less than 20% of local research findings are translated into policy.

Jeffery Garnett presented an interesting set of models showing the estimated rise in the number of people living with HIV and AIDS around the world. In the period 1990 to 2000 the rise was very steep, but had levelled off somewhat everywhere. The numbers of people living with HIV and AIDS depend on those who survive, which will be higher with adequate access to successful HIV treatment, and the number of new cases. In discussing HIV prevention, he noted that while reduction of multiple sexual partners is but one of the strategies, it is also about condoms, and it is a mistake to see anything as a '*magic bullet*'.

Later in the day, there were a number of sessions that in a sense addressed some of the issues raised in the plenary.

An abstract session had a presentation on the female condom and affirmed that it is the only tool a woman can use to protect herself from HIV. But women need to be empowered how to use it – like a bicycle or a cell phone or a computer. And men need to be familiar with the female condom – how it looks and how to use it together. The paper called *Female condom breaks gender barriers* described the training of trainers, whose jobs it was to educate women how to use the female condom – with excellent results.

In the Women's Networking Zone, ICW held a session titled *Putting 'women' back into 'gender'*, which yielded an excellent discussion on how the language we use informs the spectrum of policy, planning and implementation. '*Gender*' has been a euphemism for '*women*'. However, this has been a term for a range of meanings, often not being very specific, and could, thus, leave women '*invisible*'. At the session, participants noted the sentiment that lesbian women felt left out of this equation, and how the involvement of men needs to be carefully negotiated and crafted in the realm of gender programming. Programming on gender needs to always work for women, and the tools of gender analysis are very useful – without losing women in this activity of '*gender*'. There is a need to be specific about who we are and what we want. It was also noted that, for example, medical male circumcision programmes need to work for women. The outcome achieved by male circumcision needs to reflect the inter-connectedness of the world, '*humans are not lab rats*' – the individual protection needs to be translated and understood, if it can be applied to a community.

...policy is informed by theological beliefs and not evidence-based...

And later in the afternoon a skills building workshop was held on *Reproductive choice and HIV and AIDS* facilitated by Ipas and the Health Systems Trust. It was the first-ever session at an IAS conference to address the issues of abortion and HIV and AIDS. In addressing a human rights framework, the session reviewed international agreements, and worked on advocacy strategies to articulate these issues. The facilitators made it clear that women have the right to have the outcome of a choice to a healthy pregnancy and baby, or to choose to have an abortion. Even in instances where abortion is not legal, women have the right to have post-abortion care. This is increasingly important in cases where HIV positive women have chosen to have an illegal and unsafe abortion and, as a result, could seriously risk their lives.

Ida is a Professor of Anthropology at the University of New York Graduate Centre

Comment: We need to move beyond this

International AIDS conferences have always presented us with an ongoing struggle to have our voices heard – to claiming our spaces beyond the margins of the conference.

We need to move beyond this: have our many issues seriously listened to, our experiences and expertise acknowledged, so that we no longer have to *'fight'* for a space, but can put our energy into *'fighting'* for our rights and improving the lives of women.

Vicci Talis, OSISA, South Africa

ATHENA says Thank you!...

Thank you to everyone, who contributed to this special joint edition of the ***ALQ***, and most especially to Dr. Johanna Kehler and the AIDS Legal Network (ALN) for inviting ATHENA to collaborate. Producing a daily newsletter at the 2008 International AIDS Conference in Mexico City, and this special joint edition of the ***ALQ***, has provided us an unparalleled opportunity to assess the state of women and HIV globally; to see where the women's movement and the HIV movement intersect and fall down; and to gauge our success in utilising a rights-based framework in addressing HIV and AIDS, through the very stakeholders, who are each day at the front lines of the response, whether it be community mobilisation or public health research.

Thank you to Cynthia Eyakuze who made our work in Mexico City and the production of ***Mujeres Adelante*** possible through her shared expertise, and the generous funding of the Public Health Program of the Open Society Institute (OSI). Thank you to Maria de Bruyn, ATHENA Steering Committee member and Senior Policy Advisor at Ipas, for her work in conceptualising and developing ***Mujeres Adelante***. Thank you to our core team of writers in Mexico City, whose timely response to '*deadline*' was without compare – Dr. Ida Susser, Dr. Zena Stein, Marion Stevens, Luisa Orza, Ximena Andion, and Sue O'Sullivan. Thank you to our team of doctoral students Risa Cromer, Daisy Deomampo, Kate Griffiths, and Ted Powers, who tracked relevant sessions on women and HIV at the Conference. Thank you to Rachel Yassky, and again to Ida Susser, for their behind the scenes efforts. Our extraordinary youth team of Jonah Kreniske, Saajid King, and Aisha King tackled all, and were essential to the of the ***Mujeres Adelante*** in Mexico City. Thank you!

This global adventure was only possible because of the vision, skill and unwavering dedication of Johanna Kehler. Thank you. Melissa Smith, and the entire staff of the AIDS Legal Network, worked through the day and night to produce the beautiful and powerful forum for women's voices in the AIDS response that ***Mujeres Adelante*** represented.

E. Tyler Crone, ATHENA

Daisy Deomampo

In Focus...

Understanding sexual pleasure and desire

How do young women make sense of their sexuality within transactional sex? How can an emphasis on sexual pleasure and desire contribute to more effective HIV and AIDS prevention programming? What choices are available to HIV positive women and men, who desire and intend to have children?

The papers presented at the panel ***Reproductive Health: Sexuality, Fertility and Desire*** covered a range of often overlooked themes in discussions around reproductive health and HIV prevention. Drawing on ethnographic, qualitative and quantitative research, each of the speakers delved into emerging sexual and reproductive health and rights issues, including sexual pleasure and desire, fertility desires among people living with HIV and/or AIDS, and women's beliefs about transactional sex.

The session opened with the theme of gender, power and sexuality within transactional sex in research presented by Joyce Wamoyi. Through a discussion of the range of perspectives on sex and sexuality within transactional sex, Wamoyi revealed that young Tanzanian women's attitudes about transactional sex are not necessarily governed by poverty, but are in fact linked to feelings of autonomy, pride and a sense of value. Indeed, for many of Wamoyi's respondents, transactional sex represented a way for young women to '***equalise power in sexual relationships***', signalling the importance of understanding gender and power dynamics associated with the practice.

Issues of pleasure and desire were also brought to the forefront in discussions around empowerment of women and HIV prevention. Tsitsi Beatrice Masvawure sought to present an alternative view of women's sexuality, arguing that contrary to common belief, female sexuality, especially of African women, is not always sexually subordinate, disinterested, or reluctantly sexual. Though sexual violence and coercion undoubtedly permeate many women's lives, Masvawure argued that this comprises but one aspect of female sexuality. Indeed, through ethnographic research Masvawure reveals that young unmarried African women become active *'lust seekers'*, and embody an active '***female sexuality that has sexual pleasure at its core***.' As a result, some young women are at greater risk of HIV infection within contexts of pleasure, rather than in contexts of danger. She concludes that the challenge for HIV prevention is to explore how to develop programming that acknowledges women's pleasure, while recognising that violence, too, is an ever present danger.

Issues surrounding fertility desires rounded out the reproductive issues discussed within the session, with several panellists exploring fertility intentions of people living with HIV and/or AIDS, and concluding that further guidelines and HIV pre-conception counselling are needed to help HIV positive women and men make informed decisions about parenthood.

Each of the session's presenters offered provocative research on gender, power, pleasure and desire. How do these findings translate into effective HIV prevention programming? In the case of Wamoyi's research in Tanzania, HIV interventions should train young women to incorporate safer sex practices into negotiation for gifts or money by encouraging them to make use of the power, they believe is theirs within transactional sex. However, with regard to research on sexual pleasure and desire, further discussion on the notion of pleasure itself is needed. That is, in order to effectively take up pleasure within HIV interventions, it is crucial that we understand the various ways in which pleasure – like gender – is constructed and not taken to be a self-evident experience.

Daisy is a Doctoral Student at the University of New York.

Special report

Hilda Esquival

HIV positive women in Mexico…

One woman's voice

Everyday, the HIV and AIDS epidemic takes on more of a woman's face. The low profile of the problems faced by this sector of the population has repercussions, evidenced in the scarce provisions made for women's prevention and care needs.

The situation of Mexican women, and the gender inequalities they face, ties Mexican women to the home, unaware of the risks of acquiring HIV, and, even when they are aware, they lack the power to insist on condom use. Unfortunately, there is also the real possibility of this request being met by physical or verbal aggression, since women are always at risk of being considered '*promiscuous*', or coming across Mexican macho insecurity.

Of the total number of registered cases of AIDS in our country, since the start of the epidemic in 1983, 82% are men and 17.2% are women. But official figures show that the number of women with AIDS is increasing to one woman for every five men. The mortality rate for women with AIDS increased from 0.4 to 2.8 for every 100 thousand inhabitants. That is to say, in just nine yeas, the number of women dying of AIDS has quintupled.

It is calculated that in Mexico there are about 42 thousand women with HIV – mothers, professionals, widows, mothers of positive children, wives, peasants, women deprived of their freedom, etc.

Also, we have to mention vertical transmission, that is to say, that an infected woman can pass HIV to her baby during pregnancy, during childbirth, or whilst breastfeeding. It is very important that pregnant women are offered confidential HIV testing and counselling with their fully informed consent. Receiving an HIV test result at this point allows for the steps to be taken, which in the majority of cases prevent HIV transmission to the baby.

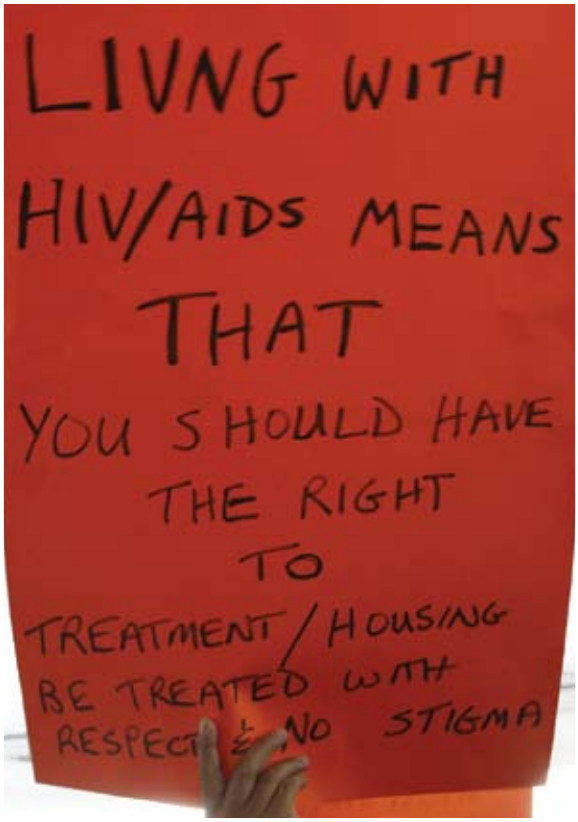
Another important issue is the right to decide whether or not to get pregnant, despite living with HIV, and even though one's partner is living with the same condition. There is now the possibility of using the technique of '*washing*' semen and taking treatment during pregnancy, which can make it possible to have a healthy baby.

Historically, women have been discriminated against, marginalised and assaulted, and in the case of those living with HIV, this makes it more difficult to attend to the problems they face. Fortunately, HIV positive women have started to organise themselves with the aims of improving their life expectancy; improving the quality of prevention and care; improving their quality of life; as well as being present in decision-making arenas that affect their lives.

…scarce provisions made for women's prevention and care needs…

Invisibility, silence and indifference will end when the brave, convinced and strong women with HIV, and those who recognise their vulnerability to it, have their views heard!

Hilda is the National Representative of ICW in Mexico.



Mari Jo Vazquez, Chair of the ATHENA Network and former chair of ICW

In my opinion...
Broadening the notion of inclusion...

I would have expected in this conference that women's issues from the region would have been more in focus. I was expecting this conference to open more to women's issues and, especially, to Latin American issues. While I know that the conference is for everybody and the conference is for global issues, I think that the Latin American women have been put aside all along. I was really expecting and will expect yet, that this issue is going to come to light.

Women's issues are a little bit more in the agenda, and positive women's issues are also a little bit more visible in the agenda. I remember when I arrived in Durban for my first International AIDS Conference. I really was high spirited with hoping that something important happen at the conference. It happened, for me. It happened as I attended the first Women's Networking Zone in Durban with the name '*Women at Durban*'. From that little beginning in Durban, we now have in Mexico the Global Village and the Women's Networking Zone. The Women's Networking Zone is very important, because it is where women's issues are going to be more addressed, and better addressed in detail, especially for HIV positive women.

I would like the epidemic to be won and I mean won in the sense of being able to stop it, fully stop it. But I don't think that this can be done without really addressing women's situations all over the world. I think that poverty should be addressed with gender imbalance, and gender inequality. All these things are put aside in the big discussions. I don't think that we can stop AIDS, without addressing those big issues somehow.

I think that we follow a model of participation, which is not really participatory. We don't really see the potential, the capacities, the abilities and the skills of everybody to be contributing at the table. Leadership is defined monolithically, while I think we should look for all the ways of contributing as leaders, not just as the kind of leader that pushes people to one ideal. We need to value leaders that contribute in very, very diverse ways and that is the same for participation. Women are not participating, because most of the time we are obliged to participate in ways that we are not able, or not willing to do. If we don't have the skills to participate, we are not invited to the table as full and equal participants.

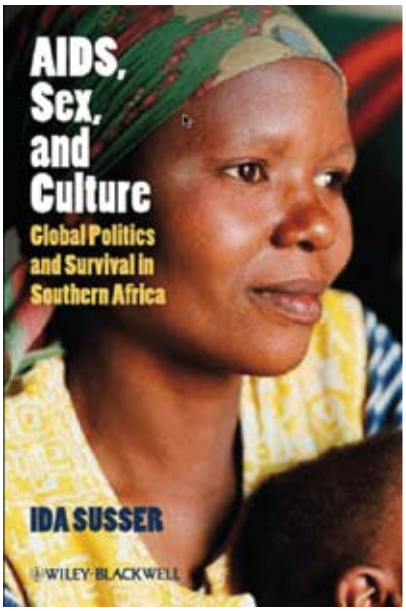
Women already have the capacity. For me, what is lacking is broadening the notion of inclusion, because most of our contributions are not well valued. It is necessary for institutions, organisations, networks, the UN system, or other networks of positive and non positive members to redefine what we think participation is, and how people can participate in very many different ways. It is important to value those ways, not just bring someone and make that person to contribute only in a very didactic way. While we need to tell people: '*ok you need to learn to be in the high-level meeting*', we also need high-level meetings to be able to include people in different ways, not just in a monolithic way.

It's amazingly hard to see a conference, a big international conference, going on in your country, in your town, talking about issues that are your own issues and you can not attend, because you cannot pay the fee for – or to be there, without having the opportunity to participate. Through '*Women at Barcelona*' and '*Mujeres Adelante'*, I felt there was the space where women were able to participate in the conference, while at the same time able to be themselves and share, hear and make use of the networking that has been happening in conferences from Durban to Mexico – building on the concept of women's inclusion and participation. I would like to see a stronger link between conferences, so that we are working together from one conference to the other, and not only for the conference.

Being at the conference is an opportunity to establish links, and to promote solidarity among different women's groups. The Women's Networking Zone is attended by very many people, and it is important to take that opportunity to make common goals, and to think of ways to work together for the future. We just lack a little bit of glue.

...we follow a model of participation, which is not really participatory...

...we are not invited to the tables as full and equal participants...



New publication…

AIDS, Sex and Culture

Global Politics and Survival in Southern Africa

By: Ida Susser

AIDS, Sex, and Culture is a revealing and provocative examination of the impact of the AIDS epidemic on women through the lens of Southern Africa. Moving from her own narrative of growing up in South Africa, anthropologist Ida Susser explores the global inequalities underpinning the AIDS epidemic; the logic of Mbeki's AIDS denialism, recurrent stereotypes of the *'Dark Continent'*; and women's fight for access to the female condom, among other issues.

Dr Susser brings together broad discussion of global conditions with the particularities of women's experiences on the ground in South Africa, Namibia, and Botswana. Ultimately, Susser argues that despite the challenges women face and the devastating impact of HIV in Southern Africa – there are *'spaces of hope'*, where women are transforming the conditions of their lives.

Ida Susser's book shows how patriarchal culture provides the ground for the formation of destructive networks of poverty, sex and AIDS. Based on Susser's cross-cultural ethnographic work, it is a masterpiece of intellectually innovative, socially relevant research. It will be a key reference for social scientists aiming to understand the world in order to overcome our current misery. It should be mandatory reading for students, academics, and policy makers around the world.
[Manuel Castells, University of California, Berkeley]

Comment: A missed opportunity for us all…

The International AIDS Conference is in itself a manifestation of the contradictions inherent in the AIDS response. The vibrancy of the Global Village and the cutting-edge conversations that were occurring within it – whether or not it was around mobilising men for gender equity, or community driven strategies to addressing gender-based violence – were literally set apart in a massive tent…a fifteen minute walk across planks and down ramps from the plush, comparatively quiet hallways of the main Conference setting.

The dialogue and *'cross-pollination'* in the Global Village was provocative and eye-opening – diverse stakeholders brought together in one space to see, learn and share in one space. Young people crowded with artists passing by protests to *'end the drug war'* – *'empower women'* – or *'de-criminalise sex work'.* This conference had an indigenous persons' networking zone, a cultural networking zone, a sex worker networking zone, a community dialogue space, a human rights networking zone, a youth pavilion, and the women's networking zone, among many more. The stretch and reach of the Global Village at the 2008 International AIDS Conference was without compare.

Yet, as in prior conferences, the conversation that was transpiring in the Global Village was not integrated with, or connected to, the discourse in the main conference halls. At the 2004 and 2006 International AIDS Conferences, the Global Village was at least placed under the same roof allowing for a sense of physical connection between science and community. So, while the presence of community stakeholders in the AIDS response is becoming increasingly rich and diverse at the International AIDS Conference, as represented by the Global Village, their voice and visibility is increasingly removed and distinct from research and science within the main conference hallways. This distance and isolation is a missed opportunity for us all.

E. Tyler Crone, ATHENA Network

Kate Griffiths

In Focus...
To transmit or not to transmit

Quoting the experience of one woman living with HIV in South Africa, advocate Michaela Clayton called upon the audience of the seminar *To Transmit or Not to Transmit: Is That Really the Question? Criminalization of HIV Transmission*, to imagine the outcome of increased criminalisation on HIV positive women facing economic dependence, domestic violence and rape:

> *…I got married in 2004, and my husband started giving me STDs. He goes out with women. When I ask for a condom or go to the clinic for treatment, he starts beating me...*

After one attempt to access HIV and AIDS services, this anonymous woman's husband, who himself refuses to test for HIV, beat her until she miscarried, in her fourth month of pregnancy.

Some women's rights organisations call for legal penalties against such violent and abusive husbands for exposing their wives to the HI virus, and for infecting them through spousal rape. Nevertheless, all of the seminar's legal experts and activists argued that such HIV-specific penalties – which are becoming increasingly common around the globe – are likely to further stigmatise and marginalise women living with HIV. Presenters argued that existing laws are sufficient to prosecute abusive men and suggested that laws, which criminalise '*wilful*' transmission of HIV, are actually likely to disproportionately criminalise women, as women are far more likely to be aware of their HIV status.

Human rights lawyer and advocate, Richard Pearshouse, drew the audience's attention to the adoption of *model* HIV laws in countries throughout west and central Africa, noting that countries tend to adopt '*the model*' wholesale from AWARE-HIV's suggestions, rather than viewing '*the model*' as mere guidance, as its authors claim. Alternatively, some countries have added language and provisions to '*the model*', which '*water down*' the model law's non-discrimination language and further criminalise various forms of '*wilful*' transmission. In two cases, in Sierra Leone and Cote d'Ivoire, '*the model*' has been adapted to explicitly criminalise '*wilful*' HIV transmission from mothers to their children, either in uterus or through breastfeeding.

Meanwhile, Julian Hows presented evidence that this increasing trend toward criminalisation of HIV is not only an African phenomenon. Presenting evidence of a detailed study of the HIV and AIDS laws and prosecutions from 53 European and Central Asian nations, he pointed out that Sweden, Austria and Switzerland are the nations with the highest numbers of cases in which HIV infected persons have been prosecuted for infecting someone else through sexual transmission. At the same time, in a number of countries, activists for the rights of people living with HIV and AIDS have begun to lobby for repeal of laws that make such prosecutions possible.

…HIV-specific penalties…are likely to further stigmatise and marginalise women living with HIV…

In addition to prosecutions of HIV positive persons for transmitting the virus, opponents of criminalisation are also concerned about the increasing number of laws worldwide, which require disclosure by HIV infected people to spouses and sexual partners; requirements that implicate health professionals in notifying the sexual partners of their patients; and compulsory HIV testing.

Kate is a Doctoral Student at the City University of New York.

Comment: We need the *'right'* women at the table

I want to move way past *'nothing for us without us'.* I want to move to *'us'* deciding it and being squarely at the centre of it. Sometimes *'us'* are homogenous; and sometimes, *'us'* face intersecting oppressions, such as homophobia or the discrimination faced by women drug users.

We need the *'right women'* at the table, not just anyone at the table. There are discrete solutions. It is not appropriate to expect one woman to speak to all the issues. Women do have a lot of commonality of issues, from gender-based violence to sexual and reproductive rights to reproductive choice. We also have a lot of diversity. I want to see women, in all of our diversity, sitting at the table and at the centre of all the decisions that affect our lives.

Louise Binder, Blueprint, Canada

Special report

Neelanjana Mukhia

Resources must not be diverted…

Male circumcision and women's rights

Recent research evidence has shown

> *…that male circumcision is efficacious in reducing sexual transmission of HIV from women to men.*[1]

While this data is welcome in increasing our prevention strategies in addressing HIV, like any other prevention strategy, this one must integrate efforts to advance women's rights.

As women continue to be at the epicentre of the HIV and AIDS epidemic, especially in Sub-Saharan Africa, it is imperative that male circumcision be seen as complementary to other ways of reducing risk of HIV infection, and not as a '*magic bullet*' for HIV prevention.

While the research shows that male circumcision is a viable strategy for the prevention of heterosexual transmission in men, it does not provide complete protection against HIV infection for women or for men. Circumcised men can still become infected with the virus and, if HIV-positive, can infect their sexual partners. Consistent condom use remains the most effective tool for HIV prevention.

The Women Won't Wait campaign[2] urges attention to essential factors as part of scaling-up male circumcision:

- There is insufficient data to show whether or not male circumcision, without condom use, results in a direct reduction of transmission from HIV-positive men to women.
- The extent to which male circumcision will lead to risk compensation (i.e., circumcised men and their sexual partners engaging in riskier sex behaviour, because of misinformation or a false sense of protection) is unknown. Risk compensation may compromise women's ability to negotiate conditions of sex (if and when sex happens, condom use, etc) and increase gender-based violence.
- The potential harmful effects of male circumcision must be monitored closely. The WHO/UNAIDS report advised

  > *…policy makers and programme developers to monitor and minimize potential harmful outcomes of promoting male circumcision as an HIV prevention method such as unsafe sex, sexual violence or conflation of male circumcision with female genital mutilation.*
- The positioning of male circumcision as reducing HIV transmission from women to men may perpetuate or reinforce perceptions of women as '*vectors*' or transmitters of disease, and may in turn, lead to increased gender-based violence or other gender-based discrimination. Prevention strategies for both men and women must be invested in, so that these are available, accessible, affordable, and of high quality. There is already a gap between HIV prevention strategies for women and men; and a scaled-up roll-out of medical male circumcision must not widen this gap. Women controlled prevention methods, including female condoms, must be made available with equal commitment and vigour.
- Criminalisation of HIV, already a harmful strategy, could become even more harmful, if a man's circumcision status is used to increase the legal repercussions women might face.

…prevention strategies… must integrate efforts to advance women's rights…

….male circumcision should never replace other known methods of HIV prevention…

While resources devoted to male circumcision seem to be growing, proven prevention methods, like the female condom for women, continue to be under-resourced. Equal and adequate funding for male and female prevention technologies is essential. These include microbicides, pre-exposure prophylaxis and vaccines, as well as structural and behavioural interventions to reduce women's risk of HIV infection.

In moving forward, it remains crucial to bear in mind that:

- Male circumcision must not

be seen as a '*magic bullet*' for HIV prevention, but as complementary to other ways of reducing risk of HIV infection.

- Communities, and particularly men opting for the procedure and their partners, require careful and balanced information and education materials that directly address the need for condom use and discuss the change in power balance to increase women's ability to negotiate safe sex and condom use.
- Further research should be conducted to clarify the risks and benefits of medical male circumcision with regard to HIV transmission from HIV-positive men to women, for men who have sex with men, and in the context of heterosexual anal sex.
- In rolling out male circumcision, it will be important to monitor rates of gender-based violence, as well as coercive sex that may occur during the period of wound healing/ recommended abstinence post-surgery and thereafter.
- There is a need to strengthen resources allocated to the integration of HIV and AIDS and sexual and reproductive health and rights programming, as well as around women's empowerment and gender equality. In addition, there is a need to ensure meaningful participation of women, and positive women in particular, in research; policy development; and, programme planning and implementation efforts, including in relation to medical male circumcision.
- It is also important to monitor resource allocation and flow for HIV prevention activities globally and within countries, ensuring that, where there is spending on male circumcision, resources are not taken away from proven prevention interventions for women. Resources must be allocated to ensure not only that male circumcision procedures are done safely, but that these interventions are also good for women in the communities where they are performed.
- Male circumcision should **never** replace other known methods of HIV prevention and should always be considered as part of a comprehensive HIV prevention package. Prevention and treatment efforts that work (e.g. condoms, female condoms, post-exposure-prophylaxis, diagnosis and treatment of sexually transmitted infections, HAART and OI treatment) must continue to be scaled up. Resources earmarked for interventions to address women's vulnerability, due to gender inequality and to violence, must not be diverted.

FOOTNOTE:
1. WHO/UNAIDS. 2007. Technical Consultation, Male Circumcision and HIV Prevention: Research Implications for Policy and Programming.
2. For more information on the Women Won't Wait campaign, please contact info@womenwontwait.org.

Neelanjana is the International Women's Rights Policy and Campaign Coordinator of ActionAid.

Comment: What would it look like to take women's lives into account?

One of the many interventions that takes women's lives into account is a '*one-stop shopping*' clinic for women and girls that includes family planning, HIV and AIDS prevention and treatment, and prenatal care. Since the 1980s, some public health activists, recognising the centrality of women's experience of reproduction to the spread of the HIV and AIDS epidemic, have recommended that family planning clinics integrate HIV and AIDS services into their routine interactions with women. As long as they included all services, from sex education for young girls, fertility planning for positive women, harm reduction programmes to well-baby clinics, this would certainly be a significant intervention.

Indeed, in 2000, this was adopted as one of the Millennium Goals of the United Nations. Mary Robinson, who was then the UN High Commissioner for Human Rights, and many others have advocated for these goals on the international stage ever since. However, such an obvious and seemingly logical, practical, and economical approach to HIV and AIDS prevention has seldom been put into practice. Since 2000, family planning itself has come under attack. For this reason, the comprehensive approach to family planning and AIDS, visualised in one-stop shopping care and prevention programmes, seems like an even more remote possibility, though still eminently worth striving for.

Ida Susser, Professor of Anthropology, University of New York, USA

Luisa Orza and Sue O'Sullivan

In Focus...

Rights denials constitute violence…

HIV and gender-based violence

The recognition that sexual violence and rape are significant factors in the growth of the HIV pandemic, especially in areas of war or civil unrest, has gained momentum over the last 6 years.

In this shared ICW – ATHENA satellite (*Moving Forward: New visions and actions to address HIV and gender-based violence*), Anne-Christine d'Adesky from ATHENA and WE-ACTx brought together a panel of activists and advocates in the area of HIV and gender-based violence to examine some of the difficulties and possibilities in responding to this '*double epidemic*'.

The session was opened by Patricia Perez, Nobel Peace Prize nominee from ICW Latina, who introduced the ICW Peace Campaign, asserting that human rights denials of all kinds constitute forms of violence. Dorothy Onyango, co-chair of ICW International Steering Committee from Kenya, spoke about the need for women to know their rights in order to claim them.

Nduku Kilonzo from the Liverpool VCT Care and Treatment in Kenya then spoke, in persuasive detail, about the need for closer engagement between the medical and legal sectors in post-rape care and redress. At best, medical and legal frameworks operate in parallel, and at worst, they can be completely divergent. An integrated perspective and approach is called for, which includes, for instance, common training approaches for health and legal service providers.

Richard Pearshouse from the Canadian HIV/AIDS Legal Network spoke about the limited role the law can play in the response to HIV and AIDS. While impotent to provide prevention, treatment and care, law can address human rights abuses that fuel and drive the epidemic. Examples of successful legislation, especially from countries within the same region, can provide effective leverage for advocacy.

Lynne Lucy from HEAL Africa in the Democratic Republic of Congo (DRC) emphasised that raped women are survivors seeking solidarity from the global community and not victims, seeking pity. She spoke personally about the horrendous scale of rape and sexual violence in the DRC. Although the majority of rapes and attacks are carried out by soldiers, she reminded everyone that 26% of reported cases are perpetrated at the family or community level. She called for a zero tolerance response to sexual violence at all levels.

Taking the different strands of the discussion, Anne-Christine d'Adesky set forth a series of questions and possible answers, which spoke to the various themes the speakers had raised during the session. She highlighted the centrality of the trauma experienced by rape survivors, often perpetuated by the services, which are intended to help – since, with every step of the way, the experience may be re-lived. Community advocates, she suggested, could be best placed to respond with the necessary psycho-social care *and* access to medical and legal redress.

…respond with the necessary psycho-social care *and* access to medical and legal redress…

Luisa and Sue are from ICW.

Special report

Motherhood without discrimination

Esther Sheehama

HIV impacts on people's ability to achieve their full sexual and reproductive health rights and sexual pleasure. The need to address sexual and reproductive health and HIV and AIDS cannot be overemphasised.

Sexual and reproductive rights are founded on the principles of human dignity and freedom, and they include that all persons have the right to sexual and reproductive healthcare and to make their own decisions about their sexual and reproductive health.

My name is Esther Sheehama. I am 26 years old, and a Namibian living with HIV for the last nine years. I was called names by the people that I trusted to be in their care; I was denied my freedom of expression, when I spoke about the rights of HIV positive women. I remember when I gave birth, the doctor had done a caesarean on me, and a few months later I found out that I was sterilised – without my consent. It happened just because of my HIV status. The doctor took away my basic right, purely because **he thought he had the power to make decisions on my behalf**. Surely, the government should be held accountable for what had happened to me, and other HIV positive women, who were denied their right to motherhood.

The virus in us does not mean we should be unable to have children, like HIV negative women. HIV positive women have equal rights to health and freedom from discrimination. HIV positive women and men want to have children. Many people ask: who will take care of the children when you die? We live in a world, where people die every second from different ailments and infections, not only from HIV and AIDS. Why should someone, who is HIV infected be different?

Our governments have a duty to uphold the global commitments to women's health and rights that they have signed. They must allocate financial resources, put in place measures to implement existing laws, programmes and policies, and put in place mechanisms to ensure their enforcement.

The 1994 historic International Conference on Population and Development (ICPD) affirmed that sexual and reproductive health is a human right that must be fully enjoyed by all. The Namibian government recently agreed to honour the Millennium Development Goals that address women's reproductive health rights, which are key to promoting gender equality and development. The Namibian HIV/AIDS Charter of Rights prohibits discrimination and calls for women's empowerment. However, the reality for HIV positive women in Namibia is that they are not treated equally to HIV negative women. The issue of forced sterilisation is a major concern, particularly for young women, and should not be ignored. What

is the global community doing about it? What action is the church taking on forced sterilisation, and what are HIV negative women going to do about the whole scenario? Doctors who perform forced sterilisation need to be held accountable, since this policy responds to mandates from a higher authority.

Tears run down my face almost every night, when I think that I will not be able to have another child. But I have to wipe my tears away and speak against the injustice that happened to HIV positive women, such as myself. I am sure that there are more women, who are wiping their tears every night, because they cannot stand up for their and other women's rights. No one wants to be responsible for the damage that was done. Even women in decision-making positions, who see the pain we go through, choose to be silent and cry behind closed doors.

Women living with HIV and AIDS must be guaranteed respect, dignity, and equality so that they can enjoy their sexual and reproductive health rights, including enjoying motherhood without discrimination.

Esther is from ICW Namibia.

Special report

Ximena Andion

Coerced sterilisation: The Chilean experience

Andrea is a Chilean woman living with HIV, who was sterilised, without her consent, while she was recovering at the hospital after giving birth to her first child. She was 22 years-old and her reproductive life had ended…

The story of Andrea is the story of many women in Chile, who are sterilised, without their full and informed consent. Vivo Positivo, the leading organisation working with people living with HIV in Chile, conducted a study that revealed the practice of coerced sterilisation in the country.

This organisation presented Andrea's case before the national courts and the decision is still pending. If the outcome of this case at the national level is not in the favour of women's reproductive rights, Vivo Positivo plans to present Andrea's case to the Inter-American Commission of Human Rights.

In words of Vasili Deliyanis, director of Vivo Positivo, '*This case is landmark for the organisation and the country*'. It has fuelled a debate on the sexual and reproductive rights of women living with HIV. This case also contributed to the promotion of a dialogue between government authorities and HIV positive women, which addresses the needs and experiences of these women. As part of its strategy to protect women living with HIV, Vivo Positivo is training women to recognise and employ their basic human rights. As Sara Araya, Gender Coordinator of Vivo Positivo states,

> *…the women that are at greater risk are the ones, who do not know their rights.*

What is Vivo Positivo expecting? Redress for Andrea and all the victims of coerced sterilisation in Chile. In addition, this organisation has a proposal that can be utilised in other countries as well – the creation of a Unit of Assisted Fertilization for women living with HIV within the health centres.

Ximena is the International Advocacy Director of the Center for Reproductive Rights, USA.

Comment: Arresting drug users…

At the Harm Reduction Zone of the Global Village, we interviewed Sam Friedman, of the National Development Research Institute (NDRI), about his challenging and path-breaking research, which shows that arresting hard drug users does not decrease the number of drug injectors. On the basis of the data from 96 metropolitan areas of the U.S. from 1992 – 2002, Freidman shows that increased arrests did NOT lead to any decrease in drug injectors. If anything, Friedman commented, increased arrests might be associated with an increase in drug injectors.

Friedman has already demonstrated in a 2006 publication that, between 1994-97 metropolitan statistical areas with higher hard drug arrest rates had higher HIV prevalence among injecting drug users in 1998. Thus, the major increase in arrests over the past decade may in fact have contributed to an increase of HIV infection.

For women, this news is particularly significant. According to Friedman, women drug users make up approximately 30% of the drug using population, and are arrested on charges of selling sex, as well as for drug use. As a result of arrest and incarceration, women are removed from their households and community and face the risk of losing custody of their children. Such procedures are already being challenged by women in these situations. The new data that arrest does not reduce drug injection provides a powerful argument against the punitive procedures now in place, which can destroy the lives of women, men and their children.

Special report

The diaphragm as harm reduction!!

Zena Stein and Ida Susser

Is it two decades that we have been searching for a way to protect women from HIV infection? For sex workers, from their clients? For married women, from their roving husbands? And all we say is: insist he uses a (male) condom; or, wait until there is a microbicide.

The uselessness of these messages is evidenced by the number of women newly infected with HIV, across the world, each day.

But still we do not make full use of what we have and know.

Consider the vaginal diaphragm. The least expensive of all the devices known, because a single diaphragm can be used and re-used for years. Easy to apply, discrete and barely noticed by the partner. So why not recommend it for harm reduction?

The reason is that, in these days of evidence-based prevention, we have no proof that it will work. For the male condom, years ago, there had been a trial of the protection it conferred – on men – against gonorrhoea – sailors on shore-leave were randomised to use it. For women with the diaphragm, there is also evidence that re-infection by gonorrhoea was reduced. But with HIV, no such clear-cut protection for either device has been demonstrated. However, we do know, from following the fate of discordant couples (one infected, one not) that if both are faithful and the male condom is used absolutely consistently, then the chances that the infection will be transmitted will be very low.

Perhaps it has been misplaced sexism that has kept both the female condom and the diaphragm from being tested in similar situations? But also, there is understandable nervousness that they give less protection. But will they give some? Better than using nothing at all? Harm reduction?

...easy to apply, discrete and barely noticed by the partner...

...perhaps it has been misplaced sexism...

Sad to say, disdain for the diaphragm peaked earlier this year when Nancy Padian a persistent, but disciplined believer in the diaphragm, published the results of the randomised control trial she carried out in Southern Africa.[1] Half the women, who participated in the trial, were given a diaphragm and (male) condoms, the others condoms only. All participants were followed carefully and counselled constantly on the use of the condom. They also regularly reported on which device they had been using, if any, at the most recent sexual encounter. In the event, analysing the results by what is known as the '*Intention to Treat*' procedure (the gold standard), each group had become newly infected (and pregnant) at almost identical rates.

So, the sceptics concluded that adding the diaphragm was not useful. The trial, expensive and extraordinarily difficult to accomplish, is regarded as a failure.

But that is an absurd conclusion. It turned out that while almost all the (male) condom group reported they used that device up to 80% of the time, the diaphragm plus condom group reported only 50% use. So how come the infection and pregnancy data were the same – try these three interpretations:

1. Condom use did not protect.
2. Condom and diaphragm use (reported by a minority) is doubly as effective as condom only.
3. Diaphragm alone is nearly as effective as condom alone.

The third interpretation cannot be proven – you have to believe that women are reporting accurately, the protection, if any, they used in their most recent sexual encounter. The strength of '*Intention to Treat*' analysis is that the analyst is free to ignore this information – but sometimes common sense trumps statistical so-called rigor. Why do so many women instructed to use condom plus diaphragm report they were using only the diaphragm? Because that is what they are doing.

And that would mean that Nancy Padian's experimental group are forsaking the male condom for the diaphragm – and they are not harming themselves thereby!

So why, and ask the pundits this question, should we not equip and advise women, who have problems in persuading their partner to use a condom, to use a diaphragm – even on the off chance that it might be helpful, and certainly could do no harm? No, say the pundits – if you give a woman an excuse to set aside the condom, a better established device, she will take the easy way out and put herself at risk with the diaphragm.

So now it is pseudo-psychology that is keeping the diaphragm out of sight – how do we know that if she is unable to persuade her partner to use a condom, she won't leave herself without any protection? That will certainly happen often enough.

So here is our proposal. Every sexually active woman be fitted with a diaphragm, and trained in its use and care. She should have it in place before every sexual encounter. The only exception is when she is confident that her partner will use a condom – or if she is hoping to conceive.

FOOTNOTE:

1. Padian, N.S. et al. 2007. 'Diaphragm and lubricant gel for prevention of HIV acquisition in southern African women: A randomised controlled trial'. In: *Lancet*; 2007 Jul 21; 370(9583):251-61; See also Stein, Z. & Glymour, M.M. 2007. 'Diaphragms and lubricant gel for prevention of HIV'. In: *Lancet*; 2007 Dec 1; 370(9602):1823.

Zena is a Professor (Emerita) of Public Health and Psychiatry at Columbia University.

Comment: Making free and autonomous decisions…

I believe that at the conference we achieved a greater understanding among civil society and key policy makers that women living with HIV and AIDS are to be in the position to enjoy their sexual and reproductive rights, without discrimination. States have the obligation to ensure that women living with HIV and AIDS can make free and autonomous decisions about their sexuality and reproduction. One of the challenges that we still have ahead is how to ensure that there are adequate monitoring and accountability mechanisms in place, at the national and international level, to ensure that governments comply with these obligations.

Ximena Andión Ibañez,

Emily Bass

Reflections…

Cutting through the hype

Take away messages from Mexico City about male circumcision for HIV prevention and the implications for women

HIV prevention and these international AIDS conferences have a funny relationship. Every two years, tens of thousands of advocates, scientists, programme implementers, and policy makers troop to the assigned meeting place to take stock of the epidemic. And, every two years – for at least the last six or eight years – there has been a specific prevention option that was thrust into the spotlight by plenary speakers and *'sound bite-makers'* alike.

It is a funny thing, because, while the intervention changes – vaccines and microbicides have each had their turn – the pattern does not. There is excitement, enthusiasm, a very valid examination of the utter failure to deliver existing HIV prevention strategies to the vast majority of people who need them on this planet, and the implied hope that this new strategy, whatever it may be, can really help turn things around.

This time around, male circumcision for HIV prevention was under the glare of the spotlight – although it shared the stage with treatment as prevention. (This means a range of things, including pre-exposure prophylaxis, the still experimental use of ARVs to reduce the risk of HIV infection in HIV negative people. PrEP bears closer examination for its implications for women – and for all people – than this article will provide.)

There is nothing wrong with the spotlight, in moderation. Each new strategy does have a role – alongside existing strategies – in turning things around. But it is never as simple as a '*sound bite*', and women around the world have been making this point about medical male circumcision for the past two years. Contributions from women were also a part of the story of male circumcision at Mexico City, though not nearly enough – and not nearly as comprehensively, as they will need to be to optimise the potential benefit of medical male circumcision programmes.

Background on the Buzz: Data from Trials of Male Circumcision for HIV Prevention to Date

In the randomized clinical trials of medical male circumcision that took place in Uganda, Kenya and South Africa, men's risk of HIV infection dropped by roughly 50 percent after they were circumcised. This risk reduction was calculated by comparing men in the '*intervention*' arm of the trial, who received circumcision along with condoms, STI treatment and counselling, with men in the '*control*' arm, who received condoms, STI treatment and counselling,

but did not undergo surgery. The studies compared rates of HIV in the intervention and control groups, and found significantly fewer new HIV infections in the circumcised, HIV negative men.

This is the individual benefit of the intervention. If male circumcision for HIV prevention is scaled-up in high HIV prevalence areas, where there are low rates of male circumcision, fewer men would acquire HIV infection, thus, reducing the risk of exposure to their female partners. This process is termed secondary protection and it translates into a potential population-level benefit for the intervention over the long-term. Medical male circumcision also reduces rates of genital ulcer disease and STIs in men; here, too, there could be a secondary benefit for women because these infections are cofactors for HIV transmission.

A separate trial in HIV positive men in Uganda looked at whether or not male circumcision of positive men reduced their female partners' risk of HIV infection. Here, there was no evidence of benefit. There was even some suggestion, though not conclusive, that women, whose partners did not abstain from sex for the four to six weeks post-surgery needed to give the wound time to fully heal, were at an increased risk of being infected with HIV from their partners.

Women Have a Say: What a new, male-targeted intervention means for us

Is there a role for women in thinking about how to introduce and talk about an HIV prevention strategy that solely involves men's bodies?

The answer is, simply: absolutely!

Successful introduction of any new HIV prevention strategy requires carefully-developed, context-specific messaging that addresses the concerns, questions and roles of all community members in implementing, accessing or understanding the new strategy. (This goes for old strategies, too, like female condoms, which are still sadly inaccessible and under-utilised world-wide).

It is absolutely critical to think about women's concerns and questions in any communication about medical male circumcision programmes. One major concern voiced by many women is that communications addressing the need for continued condom use, and other forms of risk reduction, since male circumcision is partially effective at best, and its benefits can be off-set by major changes in numbers of sexual partners or drops in condom use.

Another major concern is around stigma: will male circumcision be viewed as a '*badge*' of HIV negative status, and so increase the blame, stigma and abuse directed at HIV positive women, who are blamed for bringing HIV into the relationship?

It is also critical to think about how the programmes themselves communicate: what does it say if a programme offers services for men but not for women? Or if a programme provides medical male circumcision as a stand-alone service, versus a service that is incorporated into broader sexual and reproductive health programmes that meet the needs of both men and women? What will it say to men about the need to use condoms or reduce their sexual partners, if there is a permanent surgery, which reduces their risk of HIV infection?

...any new HIV prevention strategy requires carefully-developed context-specific messaging...

These and other questions were raised in June 2008, when over 30 HIV positive women and their allies met for a civil society dialogue on male circumcision for HIV prevention and the implications for women. The meeting, sponsored by the non-profit prevention research advocacy group, AVAC, was a companion to a World Health Organization meeting on the same topic.[1]

News in Mexico City

The Mombasa consultation on implications for women took place about six weeks before Mexico City. What did this conference add to the discussion? Here are some thoughts, based on the official presentations, and highly unofficial observations from hallway conversations and reactions to various sessions.

- **The long-term follow up on the trials confirms, and may even improve on, the original results – in the trial setting.** One of the questions that women have raised about the studies is whether or not the findings are valid. All three of the trials stopped randomisation early, following the recommendation from an independent data and safety review board. In each case, the recommendation was made, because there was such a strong difference in the rates of HIV infection between men in the circumcision arm, versus men who were asked to wait to be circumcised, that the data review board considered it unethical not to offer circumcision to all participants. When a trial alters from its original plans – in this case, all of the men enrolled were offered circumcision sooner than planned – it changes the type of data that are available.

  In a late-breaker, Dr. Robert Bailey who

helped to run the trial in Kisumu, Kenya, presented data up to 42 months, or nearly 4 years, after the trial began. The follow-up data came from volunteers, who gave new informed consent to continue being followed after the data review board recommended that male circumcision be offered to all the men in the trial. Looking over the full 42 months of follow up, the rate of new HIV infections in men circumcised during the trial was 2.6 percent. The rate of new HIV infections in men who were not circumcised, but were generally comparable – including the kinds of risk reduction counselling provided, rates of condom use and numbers of sexual partners – was 7.4 percent. The researchers also calculated the '*annual incidence*' – the average rate of new HIV infections per year in the circumcised and uncircumcised groups. They were 0.77 percent and 2.37 percent, respectively. This translated to a 65% protective effect of circumcision against HIV infection.

These long term data add additional credence to the already-strong information on the risk reduction from male circumcision in the context of clinical trials – where there is behaviour change counselling, STI treatment, and condom provision.

- **Cultural adaptation is feasible – and necessary.** Dr. Frederick Sawe of the Kenya Medical Research Institute presented on a programme that aimed to integrate medical aspects of male circumcision into traditional practices. This area of exploration is critical, as medical male circumcision for HIV prevention is being introduced, or considered, in many settings, where there is also traditional circumcision; messages about how male circumcision may reduce HIV risk for men during vaginal sex must be integrated with messages and rituals around traditional circumcision. There continues to be a great deal of confusion and misinformation about the distinction between traditional and medical male circumcision – terms that are used to distinguish the types of training, tools and surgical techniques used to perform circumcision. In Sawe's programme,

  ...medically trained clinicians are brought from health care facilities to the village and incorporated into circumcision ceremonies aiming to maintain tribal culture (but reflecting awareness of adverse outcomes associated with traditional circumcision)...

...there is nothing wrong with the spotlight, in moderation...

...it is absolutely critical to think about women's concerns...

Of note, many women expressed interest and were included in the trainings on male circumcision and prevention – an interesting, though preliminary, example of how introduction of male circumcision can be used to increase women's input and leadership in HIV and sexual and reproductive health programmes.[2]

- **Questions about rates of risk behaviour remain unanswered and must be closely followed –** The Kisumu, Kenya trial team delivered a presentation on the effects of adult male circumcision on sexual behaviour and sexual function that provided some important information on how male circumcision affects men's behaviours, like condom use and numbers of sexual partners over time. The abstract (available on-line at AIDS 2008) focuses on men's reports of sexual function and sensitivity – which were comparable in the circumcised and uncircumcised groups. Other data reported included that one-quarter to one-third of circumcised men reported having sex more often than prior to circumcision and the same proportion saying that they have less sex since circumcision; and approximately one quarter of men reported that they had not used a condom since surgery. Roughly the same proportion of men also reported feeling '*somewhat or much more protected*' from HIV and other STIs.

These data should be interpreted somewhat carefully: for example, the data on condom-use post-surgery as presented did not incorporate information on how many of those men had had sex since surgery: the low rates of condom use could have been in men who had not had sex. There also was not any information about whether the men, who were not using a condom post-surgery, had been using condoms consistently pre-surgery; and there was not any data on whether or not the men, who were having sex more often, were also using condoms more often, or whether they had increased their numbers of partners.

Even so, it is absolutely critical that policy-makers and programme implementers pay careful attention to, and act on, the implications of findings – again from a clinical trial where the messaging and follow-up is arguably far more intensive than it will be in the '*real world*'. Women have consistently raised concerns about shifts in rates of risk behaviour. As Nic Lohse from UNAIDS argued in a presentation on modelling the impact of male circumcision, these shifts may have to be very significant to off-set the protection for men. However, this is only part of the story. As women said in Mombasa:

> *…understanding how MC affects women's ability to negotiate if, when and how sex happens is absolutely essential to making these programmes work.*

- **There are many voices *within* the 'women's community'**

A lot of conversations in Mexico City happen on the fly – we were all racing from one session to another, and – at least in my case – always late. The day that AVAC and ATHENA co-hosted a discussion on male circumcision in the Women's Networking Zone, I handed a flyer to a colleague who has been working on sexual and reproductive health rights for many years. '*Come talk about male circumcision for HIV prevention*', I said. '*Male circumcision*', she repeated, looking down at the flyer in my hands. '*I'm against it*'. She kept walking.

This kind of deep scepticism and concern is one thread of the women's response. It is rooted in our history with vertical approaches and '*silver-bullet mindsets*' about other prevention and family planning strategies.

But it is a grave mistake to assume that women are all, or even mostly, opposed to medical male circumcision. The statement from the Mombasa Civil Society group stated:

> *We need prevention and treatment programmes that work for women and thus accept male circumcision as part of a comprehensive package of prevention, care and treatment. We ask that resources not be diverted from prevention and treatment efforts that work (condoms, female condoms, diagnosis and treatment of sexually transmitted infections and HAART and OI treatment) and that these be continued to be scaled up.*

…a grave mistake to assume that women are all, or even mostly, opposed to medical male circumcision…

This statement cuts to the core of what has to happen for medical male circumcision programmes to be a success by any of several measures that should be used to gauge the utility of these programmes: safety, reduced rates of HIV in men, reduced numbers of sexual partners post male circumcision, consistent or improved condom use, improved sexual and reproductive health services for women and so on.

What is of gravest concern, and where many women are in the vanguard of strong opposition, are vertical programmes that aim to provide circumcision on a large-scale relatively rapidly without integrating any of the other components listed above. While Marge Berer did not mention the Mombasa Civil Society statement, she was emphatic and eloquent on this point in her talk in the session *To Cut or Not to Cut*.[3]

FOOTNOTE:
1. To download the meeting report and other background materials, please visit www.avac.org
2. The PowerPoint slide is available on the AIDS 2008 website
3. Webcast and transcript available at the Kaiser website.

Emily is the Programme Director at the AIDS Vaccine Advocacy Coalition (AVAC).

Luisa Orza and Sue O'Sullivan

In Focus...

'If you want something for women, say *women*…'

HIV and gender equity advocates convened in the Women's Networking Zone this morning for a **critical dialogue** on the meanings of '*gender*'. Since its introduction into development-speak, '*gender*' has often faced the same fate as '*women*' – either being side-lined as an area which is of no interest to groups or organisations that do not specifically work on women's issues, or being responded to with so-called '*gender fatigue*' from people, who are '*bored of hearing women bang on about their problems*'.

Yet, more recently, the politics of HIV and development work have resulted in '*gender*' becoming a '*must-have*' in HIV programming and responses, and the word has begun to lose its political impact, and have its analytical uses obscured. Suddenly, we are facing a situation where '*gender*' may refer to any number of different groups, including men-who-have-sex-with-men (MSM), transgender groups, sex workers, LGBTI (lesbian, gay, bi-sexual, transgender, intersex people), and other sexually marginalised groups – most of which also include women, but do not refer specifically to women, or their positions within such groups. '*Gender*', once marginalised as being specifically about women, is now everywhere, but has been stripped of its analytical use. Women have become obscured within its multifarious uses and meanings.

> *If you inadvertently use the 'G' word when you mean 'women' this will steer policy and action away from women and girls.*
> [ICW staff member]

The last thing ICW wishes to do by exploring this issue is to create competition for ever-shrinking resources between different marginalised groups that now fall under the '*gender umbrella*'. What we would like to do is galvanise thinking around how to pursue HIV positive women's specific needs and interests, without these being mystified by the imprecise use of '*gender*'.

Women at the session *Putting 'Women' Back Into 'Gender' Politics* agreed that there was an important place for both the words '*women*' and '*gender*' – although among some people, there is still a lot of confusion about what '*gender*' is all about. Gender does not refer to an individual or group of people, but rather to complex and fluid systems, which influence relationships and behaviours between them. These include who has the power to make decisions, and who has access to, and control over, resources.

For example, medical male circumcision is often not treated as a gender issue, because it is not directly about women. However, as one participant in the session pointed out, if a man is circumcised, who is going to look after him during the weeks of recovery period after the operation? This illustrates but one way of using '*gender*' to understand more about the impact of a particular policy or programme.

…politics of HIV and development work have resulted in 'gender' becoming a 'must-have' in HIV programming and response…

Although there was confusion or frustration about women needing '*to fight*' for their space, when '*gender*' is used as a buzz-word for … anyone and everyone, the session ended with one of the speakers, Alice Welbourn, reminding us that a gender analysis at the individual and community level, can be a liberating experience and a powerful tool for change. So let us use a gender analysis to understand the reality of women, and others.

However, as argued by Beri Hull from ICW:
…if you want something for women, say 'women'.

Luisa and Sue are from ICW.

Maria de Bruyn

In Focus...

Reproductive health needs of women living with HIV

The Guttmacher Institute satellite speakers focused mainly on women's reproductive health needs

Morolake Odetoyinbo, of GNP+, listed many of them, including: comprehensive sex education; access to HAART, STI services, prevention methods, such as male and female condoms, affordable methods of assisted conception; access to pap smears; research addressing the effects of HIV-related treatments on women's libido, sexuality and self-image; the needs of postmenopausal women; and the need to prevent unsafe abortions, treat miscarriages and provide post-abortion care.

Odetoyinbo noted that motherhood for women living with HIV is becoming increasingly difficult – on the one hand, there are moves to criminalise perinatal transmission; on the other, HIV positive women are often prohibited from legally adopting children. She also emphasised, however, that women should not only be considered in their potential role as mothers, but as persons in their own right.

At the International AIDS Women's Caucus session, Lynde Francis of The Centre in Zimbabwe stated that many people still believe that women living with HIV should no longer think about sexuality. The assumption that abstinence should be their lot may even be internalised by HIV positive women themselves, including women who are educators and advocates. Acknowledging the right of women living with HIV to enjoy their sexuality may be one of the biggest challenges we still face.

In the Guttmacher session, Rose Wilcher of Family Health International presented convincing evidence that contraceptive use by HIV positive women can reduce the number of unintended pregnancies, prevalence of unsafe abortion and number of infected babies. Her plea to include family planning as an essential HIV prevention method was echoed by Anna Miller of the Elizabeth Glaser Paediatric AIDS Foundation, who talked about the advantages of incorporating family planning into programmes to prevent perinatal transmission. Miller described the case of an HIV positive woman, who could not obtain a safe abortion and who ultimately gave birth to a third child when she was ill, and without access to ARVs – she disappeared from the programme and the worst outcome was suspected. Heather Boonstra of the Guttmacher Institute spoke about the challenges posed to integration of family planning and HIV and AIDS services, especially highlighting PEPFAR requirements.

...the right of women living with HIV to enjoy their sexuality may be one of the biggest challenges...

What was striking about these presentations was the fact that abortion was seen as a problem to be overcome, not as a reproductive health service needed by HIV positive women, who must deal with unwanted pregnancies. No one discussed what should be done in cases of failed contraception, while Boonstra noted that conservatives in the USA are now beginning to equate contraception with abortion, forming a new obstacle to the integration of reproductive health and HIV.

It was only at the International AIDS Women's Caucus session that Elizabeth Maguire of Ipas said:

> *…We should not be afraid to say the 'A' word – abortion. Even now, in much reproductive rights discourse, this issue is often hidden or implied rather than explicit, seemingly in deference to those who still refuse to accept it as a vital part of reproductive health care. … Advocates should offer a broad vision of comprehensive reproductive health care that includes, not only the continuum of contraception, emergency contraception, post-abortion care, and abortion care…but also assisted conception for HIV discordant couples and help with adoption.*

Maria is a Senior Advisor at Ipas.

Leah Okeyo

Reflections...

If only someone would listen...

Personal reflections

In all societies, people living with HIV have numerous challenges, varying from community to community. This diverse reality has not been perfectly recognised, and therefore, making the capacity to deliver an appropriate HIV and AIDS response equally challenging.

As I reflect on my experiences at the International AIDS Conference in Mexico City, I look back and wonder at the developments that have become available in the last few years. I remember my many friends and kin who died, due to the unavailability of anti-retroviral therapy. So far, at least, I am grateful, because anti-retrovirals and better nutrition have been introduced, thus, prolonging the lives for people living with HIV. On a personal note, I count myself alive today, because of the availability of these developments. This does not, however, bar me from being in the frontline of activism for issues of AIDS, and the human rights of women. We have come a long way, but we still have a long, long way to go! I would, therefore, contribute to the loudest of my capacity on issues that touched on the same. It is sad to note that many people in the developing countries die from HIV and AIDS complications everyday, due to lack of proper access to treatment, combined with poverty.

As we all know, the effects of ARVs without food are terrible, and many have resorted to stopping the medicine all together. It is sad to witness colleagues die in large numbers due to this. If a quick and collective solution is still not found for this, I am afraid that our communities will continue to be wiped out as we watch.

What attracted me most to becoming involved in AIDS advocacy was the active involvement of people living with AIDS. I had many questions rotating in my mind, such as – *Who should be more active in the fight against AIDS? Is it the people living with AIDS or the HIV negative people?* I realised that any response, any level of intervention, prevention, care and treatment to mitigate the impact of HIV and AIDS needed the direct involvement of people living with HIV, at all levels and in all settings.

This belief was strengthened by my attendance of the Positive Living pre-conference. I cried to see how much this community, my community, struggled to put things in place. The importance of HIV prevention was stressed. Imagine a community that is already affected, laying strategies on their own, to keep the rest of the world safe! And, at the same time, pushing hard for bad policies for this community to be scrapped and replaced with ones that respected our rights as human beings.

It takes so much more time to prepare presentations,

than a non presenter could ever imagine – that is for sure. I remember, how much time I spent to put my oral presentation together – *Fighting AIDS Under Fire: HIV Programming in Conflict with Post-Conflict Settings*. I also remember the many skype calls and chats with my co-author, Anne-Christine D'Adesky, in the US and I, in Kenya. These discussions also included Anne-Christine's preparation work on a satellite session on gender-based violence and HIV. We wanted to bring the world closer together here at the conference. We strived to share with the world what different communities experience and how we could come to each other's rescue. Many times during this, and other sessions, it was noted with much emphasis, that the lack of respect for women and girls contributed more to the spread of HIV and AIDS. In my country, Kenya, and in many other countries all over the world, the struggle for equality between women and men is still '*hot*', and far from done!

The activities at the Women's Networking Zone were numerous. I saw how women, and of course men, were burning to share their passions, their experiences, their needs, and successes, all their stories, their voices – if only someone would listen! As part of these numerous activities, I was working with women and their organisations; reaching out for women and leaders to share their voices on PulseWire[1]. Now I feel a stronger need for women to get even more forums to put their heads together, and find strategies that will finally bring about change!

My amazement and disappointment escalated when I realised the number of countries that deny entry to people living with AIDS. I have heard of people corrupting medical personnel in my country, so as not to reveal the correct HIV test results. I tend to think that such people are more '*dangerous*', since they have a big secret to keep in case they get into trouble. I also feel that such policies are not practical, since the same countries allow their HIV positive citizens to travel to other countries. I cannot look at this policy as humane, and I do not believe that letting HIV positive people into these countries would be a favour to them as individuals, but a favour to the world, in terms of more participation in building the global economy. It is also a shame, when governments respect noise and protests, more than they do diplomacy.

Another of my disappointments was that I expected to hear fantastic outcomes that have lately been discovered by research, towards the cure for AIDS, or a more promising life-prolonging drug, than the ones currently available.

After the conference, I am equally curious on finding the best way to present male circumcision as a means of preventing HIV to a greater extent. This is, because many people in my community are going for circumcision in large numbers, many not knowing exactly what is entailed in this. I am also wondering aloud, if the organisations working on medical male circumcision for HIV prevention could introduce a strong follow-up system to ensure that the concepts pertaining to this are well understood.

So much has been said and done, but I still advocate for the following

- The global AIDS situation needs to be reviewed and documented
- The need for universal access to care and treatment should be treated as an urgent matter
- International desks should be availed for all HIV and AIDS emergencies, since a problem shared will always be halved
- Organisations, at the community grassroots level, should be looked at as pillars contributing to strengthen the bigger organisations
- The legal community should give as much support as possible to grassroots organisations, since their progress is always hampered by lack of sufficient legal advice and funding for the same.

  The legal community could also push, within their capacity, for '*successful*' governments to share their experiences and resources with the less '*successful*' ones. Our organisation here has realised that most drawbacks come from the fact that the rights of people living with HIV and AIDS are not respected. Rejection and stigma can hamper our work to a great extent.
- Networking needs to be stronger within countries and internationally, so as to roll-out information on a level ground
- A lot of focus and emphasis has been placed on gender, but this is not sufficient. The imbalance is still great, as it concerns education and opportunities. Women are still looked at as an '*inferior sex*'. This gap must be bridged, and the full potential of girls and women must be realised. In the absence of the woman, the world cannot exist!
- Rural communities should be represented more than it was done.

I would also wish to bring to the attention of the donor organisations the fact that communication in our rural communities is limited, due to a lack of sufficient resources. We have small organisations with great ideas and who are

...I realised that any response... needed the direct involvement of people living with HIV...

doing good jobs, but they lack stones to step on. I remember getting the conference link about the due dates from the U.S., and more advice regarding abstract submissions from Canada, at a time when organisations in the big cities were already done with everything. Something could be done, so as to enable better linking to the future.

Life has taught me to make lemonade, when I have a lemon, and I know a better recipe than this. It was fun to be in Mexico City, away from the everyday life at home, getting together for dinner with friends every evening, and meeting many e-friends and colleagues in person was a great joy! Speaking Spanish was a great experience, and the Mexicans' hospitality is admirable.

Being able to render my services, in any capacity, was quite a blessing to me. I am feeling honoured by getting physical and moral support from Anne-Christine D'Adesky, Louise Binder, Leah Stephenson, Brian Finch, Jenniffer Ruwart and Shawn and Jonah, Jensine Larsen and all the PulseWire Community, Karen Zwickert – and making many new friends and networks.

I stand out tall, over six feet, usually an attraction. I did not feel taller, for I realised I was among fellow giants, all working towards the same direction. But I enjoyed the glory of taking hundreds of photographs at request of fellow participants, mostly in my African attire!

I appeal for organisations and networks to share any available information and opportunities with the people at the grassroots. A lot of success is achieved from the work at a community grassroots level. We surely deserve, at the least, to get feedbacks and information continuously for upward growth. Without solutions to problems, identifying them would have no meaning in the first place.

The bottom line is: A greater impact will be realised, if people living with AIDS participate more in decision-making, and, especially in policy-making at the national and international level. In my walk as a woman living with AIDS, I have learned to raise my voice (many times politely) on behalf of my community, to see very bright light in pitch darkness, and to be able to identify blessings, even where there may seem to be none.

Challenges strengthen us everyday. We should, therefore, take challenges positively, but not put up with them. The winds may blow hard against us, but if we stand as a force in this course, we will bring a change in the end.

...to bring to the attention of the donor organisations the fact that communication in our rural communities is limited...

FOOTNOTE:
1. www.pulsewire.net

Leah is from World Pulse, Kenia.

Taking a stand...

Tamil Kendall, Elizabeth Shaw, Isabel Arrastia, Hilda Perez, Eugenia Lopez [1, 2]

Reflections...

Evaluating the Women's Networking Zone...

Contribution to Women's Empowerment and a Global Movement in Women and AIDS...

Among the specific objectives collectively identified by the Alliance for Gender Justice for the Women's Networking Zone at AIDS 2008 were to highlight the work and leadership of women living with HIV; engage with women from the local community; and to promote networking across sectors and disciplines and between regions and continents.

The over-arching purpose of these specific objectives, as we understand them, was to: 1) provide a platform from which to ensure visibility of priority challenges, emerging issues and good policy and programming approaches for women in areas of the HIV and AIDS response within the context of the International AIDS Conference; and 2) offer a unique conversation that would empower women through participation as speakers and listeners, and strengthen women's responses to HIV and AIDS through geographically inclusive and interdisciplinary alliance building. This article evaluates how the Women's Networking Zone contributed to increasing women's empowerment by meeting some of the specific objectives mentioned, and considers some of the challenges experienced in linking local and global women's rights activists and women living with HIV.

The evaluation draws on an analysis of the sessions held at the Women's Networking Zone (WNZ) and speakers' profiles, as well as short evaluations completed by participants attending sessions at the WNZ (n=60) and speakers (n=24), semi-structured qualitative interviews with individuals who attended sessions at the WNZ (n=9), and individual written reports, completed by Mexican women living with HIV (n=14).

GREATER INVOLVEMENT OF PEOPLE WITH HIV AND AIDS (GIPA)

The GIPA principle is defined by the participation of people with HIV at all stages and levels of programme and policy development. From the outset, a key principle organising the Women's Networking Zone programme was to be guided by the priorities identified by women with HIV, with a focus on Mexico and Latin America, and to ensure significant participation of women with HIV as speakers and workshop leaders. The first brainstorming for priority issues was conducted at a local-global meeting to promote women's full participation at AIDS 2008 that was held in Mexico City in May 2007. The meeting brought women leaders with HIV from Mexico and the region together

...a space where community women... would have an opportunity to share their experience and have their voices heard...

with activists, who had been involved in creating the Women's Networking Zone at Durban, Bangkok, Barcelona and Toronto. In addition to sharing experiences, and lobbying national decision-makers and the United Nations system for a greater commitment to women and HIV, this group generated a list of priority issues to address at AIDS 2008 that were then consulted nationally, through the Mexican network of women living with HIV, Mexicanas Positivas Frente a la Vida; regionally, through ICW-Latina; and internationally, through collaborative efforts by ATHENA and ICW Global. This framework guided advocacy efforts by allies in the scientific, leadership and community tracks of the official conference programme committees, as well as forming the basis for the construction of the Women's Networking Zone programme.

All of the participants, who completed in-depth interviews (n=9), considered that there was strong representation of women living with HIV in the Women's Networking Zone programme, as is well-expressed in this quote:

> *...Yes, positive women are represented and publicly sharing...*

Respondents also considered that the concerns of women living with HIV were at the forefront in the analysis and perspective taken on the issues during the dialogues and debates:

> *...Even though this conversation* [male circumcision] *does not directly involve them, the question was brought up about how this would affect women living with HIV...*

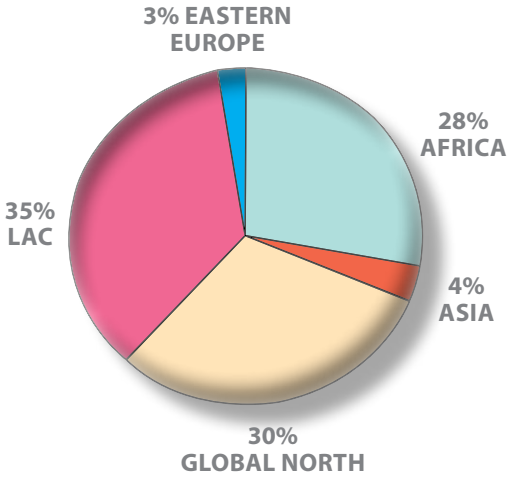
From a descriptive perspective, the key objective was ensuring that the Women's Networking Zone was a space where community women, especially women living with HIV, would have an opportunity to share their expertise and have their voices heard was achieved. The majority of sessions (75%) programmed in the WNZ included speakers/co-facilitators, who were women living with HIV.

GEOGRAPHICAL DIVERSITY, INTERDISCIPLINARITY AND INCLUSION

The Women's Networking Zone sought to promote networking and sharing of lessons learned across regions. The majority (54%) of the sessions involved speakers from more than one geographical region: Africa, Asia, Global North (North America and Western Europe), Eastern Europe, Latin America and the Caribbean, and Oceania. We also held four regional dialogues during the week: Women of Colour from the Global North, Asia, Africa and Latin America.

Another goal was to bring together different sectors of women active in the HIV and AIDS response in a constructive dialogue at the Women's Networking Zone. The individual programme evaluations (n=60) indicated that the WNZ attracted

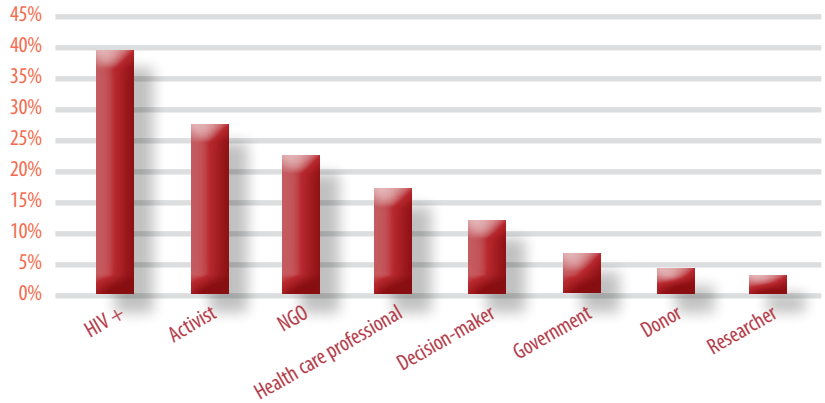
REGIONAL REPRESENTATION OF SPEAKERS



many women living with HIV, as well as community women, and provided an inviting environment for conference delegates from different sectors: 40% of the respondents said they were women living with HIV; 28% identified as community activists; 3% were researchers; 18% were medical professionals; 12% considered themselves decision-makers; 23% worked in non-governmental organisations; 7% worked with government agencies; and 5% were donor representatives (the totals add up to greater than 100% because participants could mark more than one identification/affiliation).

The Women's Networking Zone also specifically reached out to women's groups that have been marginalised and silenced in some expressions of mainstream feminism, and overlooked, to some extent, in women's responses to HIV and AIDS – sex workers, transgender women, lesbian women, drug-using women, and indigenous women. We sought to go beyond what may be commonly perceived of as '*women's issues*' by inviting women identified with these groups to participate as speakers in the Women's

PARTICIPANT SELF-IDENTIFICATION



Networking Zone and by framing the promotional materials for the WNZ to include women, who are frequently excluded, for example by explicitly including transgender and sex worker women.

That this type of inclusion is unusual was specifically mentioned by several speakers, including one of the sex worker activists who participated in the dialogue on sex workers living with HIV at the Women's Networking Zone. We believe that overcoming marginalisation, invisibility and stigmatisation of vulnerable women within the women's movement in the context of HIV and AIDS is crucial for strengthening our responses. These initial contacts and tentative first steps can be considered one step in the right direction, while future alliance building should go even further.

The WNZ was successful in creating dialogue and workshop spaces that included women from many regions in terms of speakers, but only partially successful in involving participants from different regions. There was a particularly marked divide between '*international*' sessions and '*local*' sessions:

> *...I felt like when there were dialogues with international speakers it was an international audience, and when there were local speakers, Spanish speakers, it was mostly Spanish-speaking participants. I think the kinds of dialogues were diverse but the participants were not...*

Language and geographical divides persisted despite offering simultaneous translation from Spanish to English and vice versa in all sessions. The evaluation team observed that when one of the speakers/co-facilitators spoke in Spanish, Mexican women were more likely to participate and ask questions. Mexican women living with HIV reported that the continuous availability of simultaneous translation in the Women's Networking Zone encouraged them to spend more time at the WNZ, than in the main conference, where the predominance of English sessions limited their learning and interaction. Future programmes might try to match international speakers with presenters from the host country or region, and to encourage bilingual or trilingual facilitators to use the language that is being used least frequently on the panel to encourage participation.

DIALOGUE AND NETWORKING

The Women's Networking Zone sought to foster dialogue between facilitators and participants. The individual evaluations (n=60) indicate that women were engaged by the facilitators and felt comfortable sharing their opinions and experiences at the WNZ. Specific spaces for networking were created physically (a lounge area) and in the programme (coffee in the morning, cocktail in the evening). Most participants who completed in-depth interviews said that they did carry out networking activities, and one considered that

> *…it would take an immensely shy person not to network. The space was provided.*

...reached out to women's groups that have been marginalised and silenced in some expressions of mainstream feminism...

...this type of inclusion is unusual...

One woman did comment that the physical space was not adequate for networking:

> *…Not really: it was really noisy; too spread out space; space and sound made it a challenge to network.*

Other informants noted that initially, participation by women from the Global South was limited. Another participant noted that while translation overcame the language barrier with respect to speaking about HIV, language was still a barrier to getting to know other women personally, and creating the kinds of relationships that can lead to ongoing collaborations.

In terms of sustainable, virtual linkages, the WorldPulse Media Lab provided a forum for women to continue to register on an international internet- based network, which will allow women to continue to work together. A participant noted:

> *…WorldPulse – that whole technology is to network on the international level.*

While we heard that internet-based education and organising has been effective in some rural areas in Africa, for example Kenya, our experience in the Mexican context has been that web-based communication and organising have not been very effective, because many community women do not use email regularly even after learning how to do so.

From our experience coordinating national outreach from the local host organisation, we identified communication challenges to linking the local with the global and promoting local women's participation. While it is essential to work in the local language, as well as in English to promote local and regional women's participation, multiple languages are challenging in terms of the amount of communication work it creates (translation) and limiting the ability of monolingual activists to connect. This communication

challenge was exacerbated by the centrality of internet communication for international organising and increasingly short turn-around times as the conference approached. In this context, the initial face-to-face meeting held in 2007 to develop thematic priorities and build relationships, and the extensive national, regional and international consultation, feedback and validation that took place over a period of months were absolutely essential for providing a framework and principles within which smaller working groups could make decisions.

These consultations and processes of outreach were also important for creating a sense of local ownership, but ultimately this latter goal was only partially achieved. Our analysis suggests that this is largely due to the huge experience and knowledge gaps between local women – who may never have attended a conference before, let alone participated in decision-making about the construction of a programme taking place within an international conference, and do not use the internet regularly – and the understandings and communication practices of activists, who are engaging with international advocacy as part of their everyday realities. As local organisers we emphasise the need for increased mentorship by women, who have experienced other conferences, and other Women's Networking Zones to strengthen the participation of women who are involved for the first time. This mentorship must reach across and overcome differences in culture, language, access to information technologies, HIV status, ethnicity, occupation and knowledge of the scientific methodologies that dominate the formal structures of the International AIDS Conference. Even greater efforts must be made to invite the voices of local women with HIV, so that the experience for greater numbers of women is not only learning, but also sharing and teaching.

...overcoming marginalisation, invisibility, and stigmatisation of vulnerable women within the women's movement... is crucial for strengthening our response...

UNIQUE CONVERSATIONS AND CONTRIBUTIONS TO WOMEN'S EMPOWERMENT

The Women's Networking Zone sought to host a '*unique conversation*' that involved women who were not taking part in the formal conference proceedings, and to provide a forum for issues and perspectives that might be missing from the main conference programme. Participants in in-depth interviews noted that in the WNZ they

> *...heard about themes that are not talked about in the main conference...*[and that they]*...came to the WNZ to get some gender perspective...*

The existence of a full programme of events at the WNZ was considered key for creating this unique, multidisciplinary discussion that involved women from different sectors of the response to HIV and AIDS, as well as from different parts of the world:

> *…The formal* [WNZ] *programme successfully brought information down to the grassroots level, to the local community. Although the space around was kind of crazy, it was semi-formal. It could have been local women with HIV 'stand up and share your story'. But it brought scientific information and debate and dialogue in addition to the sharing of experiences...*

By providing this unique, multidisciplinary space, the women interviewed felt that the Women's Networking Zone contributes to women's empowerment in the response to HIV and AIDS. Specific aspects that were identified included disseminating information and providing a space for networking and sharing experiences between advocates and activists from different cultures and countries. The discussion that takes place at the Women's Networking Zone:

> *…allows for change in approaches as needed, an opportunity to share with others and get feedback...*

Women identified dialogue as critical for the

alliance building and debate that can catalyse and support processes of empowerment:

> *…Anytime women get together to talk about issues, this contributes to empowerment; you can think by yourself, but this creates needed dialogue and disagreement...*

Another aspect of the WNZ that was identified by participants as promoting women's empowerment was the fact that women create the agenda, and are the majority of speakers and participants:

> *…Definitely, women are those who represent, live, speak about and share their perspectives in this space...*

The experience of belonging and comfort in the Women's Networking Zone was contrasted with the sterility and impersonality of the formal conference programme:

> *…I felt like an individual in the big conference and in the Women's Networking Zone, I felt I belonged to a community...*

The old adage '*the personal is political*' seemed to provide one of the foundations for women's empowerment at the WNZ:

> *…It speaks to our issues on a personal level and gives us options for political organisation...*

CONTRIBUTING TO A GLOBAL WOMEN'S AIDS MOVEMENT

The need to build linkages between HIV and the women's movement was a recurrent theme in the Women's Networking Zone discussions and several sessions directly tackled the issue of whether or not there is a global women's AIDS movement. Overall, in many countries and internationally there continues to be a gap between women working in HIV and more traditional feminist and women's rights movements. There are very few HIV organisations that work specifically on issues of women and HIV. One speaker noted that there

> *…is an elitist feminist movement that doesn't fight against AIDS because they don't acknowledge the feminisation. If you are a feminist and claim to be fighting for women's rights, you should be fighting AIDS, because gender inequity makes women vulnerable to HIV...*

While collaboration was expressed as a goal and some good practices were identified, for example, feminists and HIV activists working together to respond to gender-based violence in Brazil, yet frequently, women with HIV and feminists seem to be working at cross-purposes. For example, one of the issues that emerged from the Dialogue on Women and HIV in Asia is that women's groups in the region have vociferously promoted laws that criminalise the transmission of HIV as a means of '*protecting*' women from HIV infection. However, the experiences of women living with HIV from Asia, Africa and the Global North, shared throughout the five days of sessions, illustrate that criminalisation does not protect women, but rather makes the most vulnerable women, such as women living with HIV, women who suffer gender violence, sex workers and injection drug users, more vulnerable to violence, incarceration, and stigma.

…there continues to be a gap between women working in HIV and more traditional feminist and women's rights movements…

The Women's Networking Zone self-consciously sought to bring together women working in HIV with women working more broadly for women's rights. Indeed, this bridging is an explicit goal of the ATHENA Network, a member of the coalition that convened the WNZ, and an implicit objective of other coalition members. At the macro level of organisation we can see how the linking of broader women's movement and women with HIV was achieved during AIDS 2008 – for example, by looking at the speakers at the International Women's March. The speakers were women living with HIV of different ages and from different regions of the world, a representative of a large, mainstream women's organisation (the YWCA), the head of a government women's programme, a well-known Mexican feminist activist, and national and international artists. At an intermediate organisational level, we can appreciate

how dialogue and getting to know more about the realities lived by other women and the objectives of their struggles, both formally in the Women's Networking Zone programme and through informal networking, can contribute to joint advocacy agendas. It is our opinion that the inclusion of women with HIV, and other affected women, in shaping the agendas of the local, national and international women's movements is crucial, and we feel that the WNZ at AIDS 2008 made a significant contribution in this regard through enacting GIPA principles and including marginalised and vulnerable groups of women in the programme, while also including organisations that work more broadly in the field of women's health and rights.

CONCLUDING REFLECTIONS

This evaluation suggests that the Women's Networking Zone was successful in advancing the meaningful participation of women, especially the most affected women, within the context of the WNZ and the conference. The large numbers of speakers and participants, who were women living with HIV, demonstrate the strong focus on the leadership of women living with HIV and the actions that they are spearheading

...offer a unique conversation that would empower women through participation...

in the community. Mentorship and medium-term relationship building are needed to further support local women with less experience in international organising, to participate fully.

The Women's Networking Zone at AIDS 2008 also made important progress in reaching out to, and including, vulnerable groups that are often marginalised in the women's response to HIV and AIDS, such as sex workers and injection drug users. The profile of the participants who completed evaluations demonstrates that the WNZ was an inclusive forum, where community members, advocates, policy analysts, decision-makers, service providers and researchers shared and learned together. Participants felt that the Women's Networking Zone provided a welcoming space and substantive programme that promoted multisectoral dialogue and women's empowerment.

FOOTNOTES:

1.Tamil Kendall[1,2,3] Elizabeth Shaw[1,2,4] Isabel Arrastia[1,2,4] Hilda Perez[1,2,] Eugenia Lopez[1,2]
(1) Balance. Promoción para el juventud y desarrollo, AC. Mexico City, Mexico; (2) Alliance for Gender Justice at AIDS 2008; (3) University of British Columbia, Kelowna, BC; (4) Loyola Marymount University, Los Angeles, CA.
2.We would like to thank Maria de Bruyn, Luisa Orza and Tyler Crone for their input on the initial evaluation instruments and UNIFEM-Mexico and UNFPA-Mexico for their ongoing support.

Tamil is a Co-Coordinator of the Alliance for Gender Justice.

Comment: The power of collaboration

This Global Village really engaged the power of collaboration and culture. The Global Village was, in and of itself, an expression of how *'powerful culture'* is as an expression of our human potential to create a new world. Culture can also powerfully bring people together to create a new world in new ways, especially women from all walks of life, who are leading the way in imagining and creating a new world of equity, justice and inclusion.

Betsi Pendry,
The Living Together Project, South Africa

Comment: Omitting the term 'rights'...

Activists need to expand the rolling-off-the tongue term *'stigma and discrimination'* – it is too narrow a framework and it does not name more of a range of violations that our movements are already doing advocacy on, including violence. And because it omits the term *'rights'*, it misses the opportunity to use language of accountability. Activists should be better suited advocating for *'stigma, discrimination and other rights violations'*. That says more of what we mean, and it implies that people have rights to make demands from the state.

Cynthia Rothschild, USA

Ana Francis Mor, Actor and Director, Reinas Chulas[1]

In my opinion...
Telling stories...

Reinas Chulas, a group of four women performers, has been together for over ten years. We started together as theatre students and decided to move in our own direction, after it was clear that the *'beautiful'* girls move onto TV, and the *'smart ones'* go into serious theatre. We did not want to accept either of those categories for who we were, or for the kind of theatre we could create; so we looked for other models that would give us more freedom and would be fun.

We also wanted to do a kind of theatre that did not just relate to our audiences, or ourselves as just '*big heads*', as we believe that, if we do that, we miss out on our souls, and our pleasures. Our heads are just one part of us. My knees are a part of me too; they are where my humour is. My inspiration is in my shoulders. My whole body is an expression of who I am as a woman, in my culture, with my education, and in my soul. So we began to do satire, as it was more expressive of all of who we are, and allows the same thing for audiences too.

We wanted to be able to share this experience and view – that we need to work hard, but we also need to be able to laugh and enjoy life, and that is what culture gives us.

Laughter is like an orgasm, it is a full body experience; it allows you to express many things at once. We wanted to be able to tell our stories, that of ordinary Mexican women, who work hard; struggle; have kids and husbands and not enough money; experience the injustices of our systems; and also give our audiences a chance to laugh and feel their own power and dignity. Being on stage gives stories the dignity and respect they need, especially stories that are ignored or disrespected by the rest of society, it gives the audience a chance to see it, and relate to fellow audience members in a new way.

Satire and laughter help audiences, especially women, to have different responses to the stories of our lives, we see changes in our audiences, because of the satire and humour. Families talk about things they would not be able to; women talk with their husbands, and with each other. We create the stories ourselves, from our lives and the women we work with. Our stories have an ability to show hard, painful things, without being insulting, it can be like good family jokes. How we are on stage shows others that they can perform too, they can also laugh, have pleasure and enjoyment in life, learn to laugh at life, as well as struggle to change it.

We learned from the best, Tito Vasoncelos and Jesusa Rodriquez. They taught us that it is possible to not only create the stories that we wanted to tell, but to tell them in ways that are sexy, powerful, fun and bring politics and pleasure together for both the performers and audience.

...we looked for other models that would give us more freedom and would be fun...

...laughter is like an orgasm, it is a full body experience...

FOOTNOTES:
1. Reinas Chulas is a partner organisation of the Women's Networking Zone and the Cultural Networking Zone.

Doris O'Brien Teengs

In Focus...
We need a voice!

The Indigenous Zone of the Global Village is a place for the indigenous populations of the world to express sisterhood and brotherhood. Four women – from the North in Canada, to Mexico, and down to Chile and then West across the ocean to New Zealand – came together to share their experiences, and one theme came with them – We need a voice!

Each of the women spoke to their nation's experiences of colonialism and the painful legacies that we, as indigenous women, live with. The rape of our land and cultures continues to affect our communities. HIV is the latest of these '*unnatural attacks*' on our harmonies; and it is moving fast into our communities. For example, the rate of HIV among indigenous women in Canada is 60% of all new HIV infections among the indigenous population, which are 22% of all new HIV infections in Canada, while the indigenous population only accounts for approximately 4% of the entire population.

Doris Peltier's voice could probably be heard screaming '*NO!*' – not only across the Global Village, but out to the world and back to Canada, where she came from. She found her voice, when she was 90 pounds and refused admission to a hospital in Canada. She would not accept their answer and screamed '*NO!*' – and then was admitted to the hospital. In so doing, saving her own life and creating a voice, by example, for many women.

Marina Carrasco of Chile spoke to the need to find other positive women to speak to, and network with, in Chile. She asked: where is the movement for human rights for indigenous people and, particularly for indigenous women? She also stressed that we need to recognise the connections for all of the advocacy calls and networks, including movements and initiatives advocating for equality, for human rights, for indigenous peoples rights, for the rights of people living with HIV and AIDS, and for women's rights.

...we need to recognise the connections for all of the advocacy calls and networks...

Eva Gomez Santiz Lopez of the Chiapas in Mexico expressed the need for indigenous women to not only have a voice, but also a space to assert themselves, as generally men have social and cultural power in their relationships. The lack of knowledge and education around sexual health and rights is overwhelming, but women are starting to talk to other women, and the next generation.

Marama Pala of New Zealand started with a traditional song. She expressed a heartfelt *thank you* to the sense of sisterhood and being able to talk about her experiences of living with HIV, especially since when she is in her homeland, there is '*no space to talk about it*'. Her fervent wish is that she is able to continue with the support that she received during the conference, when she gets back home.

Whilst our experiences, as indigenous women of the world, are unique, we share many similar histories. We are living on our ancestral homelands, with a whole new culture and medium that is not our own. As such, HIV is not going to stop us from uniting with, and bringing together, other sisters to the '*fight*' against HIV and AIDS.

We have survived many epidemics and colonisation. And now, that our voices are together, we are even stronger.

Doris is the Outreach Worker for the Ontario Aboriginal HIV/AIDS Strategy, Canada.

Special report

Mmapaseka 'Steve' Letsike

Lesbian women are often 'invisible'…

It is not about identity crisis, nor clarifying the gender presentations. It is about recognising the difference and representing the broader voices and rights of all women, including the lesbian women around the globe.

Often women's sector discussions, caucuses and conferencing are discriminatory, due to the fact that a certain group of women, who prefer same sex, are neither accommodated nor recognised in topics and debates. Why?
I believe there is a certain level of incompetence amongst many people dealing with, and addressing women issues, specifically issues that affect the lives of lesbian women, issues of HIV and AIDS, gender and sexual orientation and human rights. Although these issues affect women the most, interventions to address these often exclude lesbian women.

For instance the South African Constitution, much applauded and celebrated, recognises the fact that the dignity of the individual is both an objective that society must pursue, and it is a goal which cannot be separated from material well-being of that individual. Yet, the sexuality of lesbian women and their relationships have continuously been de-prioritised and trivialised, both in public and scholarly discourses, with limited studies undertaken in these areas. However, contrary to prevailing perceptions, some studies are emerging that suggest lesbian women do indeed test positive for a number of STIs, including HIV.

Although international studies have shown that identified lesbian women are at low risk, this does not necessarily apply to South African lesbian women, as sexual practises of lesbian women do not make them immune from contracting HIV and other STIs. In addition, high levels of gender-based violence and hate crimes directed at lesbian women, particularly in South African townships, increase their vulnerability to HIV infection.

Lesbian women's health is often *'invisible'* in most of the debates, with the result that lesbian views are not included in decisions about how to address inequalities in the healthcare sector. Highlighting the diverse range of health issues affecting lesbian women will further provide valuable evidence for policy makers, practitioners, community groups, and others – ensuring that all lesbian women's realities and needs are included in future health and education service planning.

A wide range of research papers, policy and practice documents from international sources have been reviewed – indicating that many LGBT people are likely to experience health inequalities, or social exclusion, as a result of prejudice and discrimination. These factors are likely to affect individuals differently – depending on age, class, disability, gender, ethnicity and social circumstances – while there are common experiences and barriers for accessing adequate healthcare services. Limited and/or denied access to healthcare is not only a violation of rights, but also constitutes a risk to lesbian women's health. In addition, incidences associated with homophobia and hate crimes, including rape, have serious, long-term negative consequences, both medical/health and social consequences, for individuals subjected to these forms of rights violation and abuse. As a result, concerns and fear of homophobic attitudes often lead to a situation of delaying or avoiding seeking healthcare.

There also seems to be an implicit assumption that *'overlooking'* the protection of human rights will reverse the pandemic. However, the solution to the HIV and AIDS pandemics are not as simple as making every person test for HIV and disclose their status. The AIDS pandemic is highly complex and requires deep-rooted and long term societal changes, such as gender equality, freedom of expression, and an end to poverty and hate. Ignoring this in a short-term will only delay reversing the pandemic, cost more money, and, most importantly, more lives.

…discrimination and all related hatred…is a matter of institutionalised power and control…

The fact that lesbian women are often ignored needs to be part of the agenda. There is a need to develop a deeper understanding of lesbian women's realities and needs. In order to alleviate discrimination and all related hatred, and most of all ignorance – all of which increases lesbian women's HIV risks. Discrimination and all related hatred is not a matter of individual attitudes per se, but instead it is a matter of an institutionalised system of power and control over people's sexual orientation, gender identity and ethnic diversity. As such, eliminating discrimination and homophobia needs to become a priority and responsibility of every woman, and not only a concern for lesbian women.

While there is a need to highlight the importance of interventions responding to especially lesbian women's HIV risks and vulnerabilities, there is also the urgent need for women's rights discourses to become more inclusive of lesbian voices.

'Steve' is the Sexual Health and Rights Coordinator of OUT LGBT Well-Being, South Africa.

Rachel Yassky

In Focus...
Pacific Islanders make waves

Walking through the Global Village, I found myself drawn into the leafy palms, colourful pillows and cosy straw mats of the Pacific. There I met Jovesa Saladoka and Robert Verebasaga, who invited me into their tropical environment.

Robert Verebasaga represents the region's comprehensive inter-governmental effort, the Pacific Regional Strategy on HIV/AIDS. Robert described the Regional Strategy, expanded for 2009 – 2013, which constitutes the 26-member countries' framework for ensuring coordination and priority-setting. Harmonisation and minimising duplication of resources and efforts are key challenges for a region composed of island nations stretching over thousands of miles.

Challenges notwithstanding, Pacific Islanders are eager for the international community to recognise them in the global epidemic. When asked about his goals at the Mexico conference, Jovesa Saladoka identified the importance of showcasing the Pacific Region's isolation from the global community. While the Region may represent a small fraction of the global epidemic, it demands the same attention – ***'We are just as vulnerable as everyone else'*** – he commented.

Talking about the Region's successes, Jovesa, a behaviour communication specialist at the Secretariat of the Pacific Community's HIV and STI Section, lauded the popular '*edutainment*' TV series *Love Patrol*. A popular theatre company, called Wan Smolbag, worked with the Pacific Regional HIV and AIDS Project to develop the mini-series, which was fantastically received.

…harmonisation and minimising duplication of resources and efforts are key challenges…

Jovesa reflected on this phenomenon; he sees the success of the series as an indication of the value of fostering and enabling environment for public discourse. Creative communication strategies are instrumental in stimulating positive public exchange.

…the value of fostering and enabling environment for public discourse…

However, he also underscored the value of *negative* responses to HIV messaging strategies:

> *…at least we know people are active…and then we know that people are beginning to talk, and formulating a response...*

Behaviour change communication practitioners should be alert when such a response takes place, as these are the moments determining next steps in developing responsive strategies.

Rachel is a member of the ATHENA Steering Committee.

Special report

HIV and women who inject drugs…

Sophie Pinkham

Women who inject drugs remain one of the world's most vulnerable populations.

In addition to the discrimination and health risks associated with injecting drug use, women who inject drugs face gendered inequalities. In countries as diverse as Ukraine, Kyrgyzstan, Indonesia, Morocco, and the United States, growing numbers of women drug users experience similar problems. They are often dependent on men to help them obtain, prepare, and inject drugs, and to protect them from violence on the street; unfortunately, this protection often comes along with domestic violence and a partner's refusal to wear a condom or to avoid sharing needles. Some men even prevent their female partners from visiting harm reduction sites or entering drug treatment. Studies in a number of locations have shown that women, who inject with men, often inject last and with a shared needle. Many women drug users rely on transactional sex to survive, and financial desperation, stigma, and ill health force many into the most dangerous and poorly paid types of sex work. Harsh drug policies expose women to police abuse and incarceration in prisons, without access to health services. All of these factors have a direct impact on women's vulnerability to HIV. A study of European countries found that women injectors were 50% more likely than men to be infected with HIV.

And yet, women drug users often find that they have nowhere to turn for help. Doctors, politicians, communities and even family members judge them harshly for their perceived failure to fulfil their roles as wives and mothers. As a result, many women drug users keep hidden, avoiding healthcare providers and even other drug users. Active users who become pregnant –particularly those with HIV or hepatitis C – are often pressured to have abortions, or to give up custody of their children. Access to prevention of mother-to-child transmission (PMTCT) of HIV services is poor, even in countries that have declared universal access to PMTCT. At one of the satellite sessions of the 2008 International AIDS Conference in Mexico City, Ruslan Malyuta of UNICEF explained that in St. Petersburg, where ART is relatively well-funded, only about 50% of pregnant intravenous drug users (IDUs) receive PMTCT. In Ukraine, women with a history of injecting drug use were found to be 50% less likely, than other women, to receive PMTCT.

…many women drug users keep hidden….

…healthcare providers continue to stigmatise or reject women drug users…

Healthcare providers continue to stigmatise or reject women drug users, and few programmes have staff members who reach out to those who are reluctant to see a doctor, or whose addiction has made the threshold to access too high. There are few links in most countries between women's health services and substitution treatment with methadone and buprenorphine, depriving women of essential support in managing their addiction and achieving better health outcomes. In Russia, substitution treatment is simply illegal. In Russia and Ukraine, a diagnosis of drug addiction is legal grounds for loss of custody, creating a perverse disincentive to seek care. Women who enter inpatient rehabilitation must leave their children with a family member or friend, and are often not in a position to regain custody when they come home. Around the world, many rehabilitation centres do not even accept women, especially when they are pregnant and/or HIV positive.

Meanwhile, there are all too few programmes that give drug

using women the support they need. One exception is *MAMA+*, a programme for HIV positive pregnant and parenting women, many of whom are drug users, which was presented by Anna Shapoval during a session at the 2008 Conference. Pioneered by Doctors of the World in Ukraine and Russia, *MAMA+* offers a wide spectrum of services, ranging from basic material assistance and counselling to legal aid and referrals to ARV and drug treatment. Using a multi-disciplinary case management team and a personalised approach, *MAMA+* builds bridges between the many social and medical services needed by its clients, showing that HIV positive drug using women can be '*successful*' mothers, when they are given the support they need to care for themselves and their babies. Where before, as many as 20% of HIV positive women in some Ukrainian sites once gave up their children to institutions, 95-99% now keep their children within their families.[1]

Because internalised stigma and low self-esteem are important ingredients in women's unwillingness or inability to seek care, it is essential to take measures to empower women drug users and teach them how to take control of their own health. Indonesia's Stigma Foundation recently began a new project, *Femme*, comprised entirely of women drug users and female partners of drug users. *Femme* members participate in workshops and self-support groups, where they talk about sexuality, relationships, and gender, building social identities and networks that are structured around women. *Femme* is currently developing a project that will reach out to women drug users in several areas of Indonesia, seeking to develop leadership skills and self-determination and increase women's access to care.[2]

While there has been some progress in support for gender-sensitive harm reduction, there is still a long way to go. With the numbers of women drug users increasing continuously, it is essential that governments, funders, and advocates ensure equal access to healthcare for this highly vulnerable group.[3]

FOOTNOTES:

1. For more information on MAMA+, please contact Vandana Tripathi, Doctors of the World, at vandana.tripathi@dowusa.org
2. For more information on FEMME and the Stigma Foundation, please contact Sekar Wulan Sari at kupukupusore@gmail.com
3. For more information on women and harm reduction, please visit www.soros.org/harm-reduction

Sophie is the Programme Officer at the International Harm Reduction Development Programme of the Open Society Institute (OSI).

Comment: Mothers can be heard…

This is my first time to be in an international AIDS conference. I am overwhelmed, first of all, by the number of people here, I didn't believe it would have this kind of people. And secondly, I've got to meet many different kinds of people – friendly, not so friendly, those who have good information and want to share their information.

My organisation, the Mamas Club, has come out to be known, because of the Red Ribbon Award and for the great work it is doing at the grassroots levels, especially as far as helping HIV positive mothers and their children are concerned. The mothers have been able to network with other HIV positive women, and they have been involved a lot in the dialogue with other grassroots level community organisations.

My experience so far is good, though a lot of crazy things are happening here too. It is for a good cause and everyone wants to be heard and to stand out, to know how they feel and what they should know about the HIV epidemic. I really expect to learn more from the different sessions, from the different people that I have met, and to share my experience with working with HIV positive mothers – to see, if there is a way that mothers can be heard, and the voices of their children.

Maria Natukunda, Mamas Club, Uganda

Luisa Orza

In Focus...
Empowerment needs to go beyond HIV...
Women and HIV in Asia

HIV and AIDS continue to be described as a concentrated epidemic in Asia, with interventions focussing primarily on prevention among *'high risk'* groups, such as men having sex with men (MSM), intravenous drug users (IDU), and sex workers.

Yet, patriarchal systems; the low status of women vis-à-vis men; and law and customs, which give women limited or no rights to own and control property, result in compromised livelihoods and security for women, continue to leave women, generally, in a vulnerable position in many parts of the region.

In the **Women's Networking Zone**, prominent women activists Chandika Ratri, Anandi Yurvaj, and Jaya Nair, discussed critical issues in the region. Does the recently released Commission on AIDS in Asia report adequately reflect the realities on the ground? An important omission, asserted Ratri, was the situation facing migrant workers and refugees. Migrant workers – 80% of whom are women – often find themselves alone and isolated in their destination countries, far from families, husbands, partners, and children. They may be susceptible to engaging in casual sexual relationships to relieve their loneliness. Women in domestic service report frequent incidences of coercion into sexual relationships with employers, and experience high rates of sexual harassment. Furthermore, language barriers may inhibit women's already limited ability to negotiate sexual engagement, including condom use. Access to services and information may also be impeded by language barriers, working conditions, or lack of familiarity with the local area. Refugees in many situations face similar challenges, as well as high rates of sexual violence within refugee camps.

Despite the recognition that HIV transmission among women in the region occurs through marriage, all the speakers felt that the programmatic focus on '*high risk groups*' resulted in a dearth of interventions that reach out to women-in-general, who often do not feel themselves to be at risk. Interventions that focus on MSM, IDU, sex workers and their clients, rarely acknowledge the risk that these behaviours pose to wives and partners, who tend to fall through the programmatic gaps.

...empowerment needs to go beyond HIV...to reach all areas of women's lives...

Participants at the dialogue debated the women's empowerment approach that some countries in the region are beginning to adopt, versus integrated strategies that work with both women and men, thereby creating an enabling environment for women to exercise newly acquired knowledge of their rights. Women first need safe spaces in which to reach a level status with men, be aware of and able to express their rights, and be properly informed, before women and men can work together on an equal footing. What chance is there of implementing an integrated approach, asked Jaya, if a woman cannot even speak to her husband about sex? And empowerment needs to go beyond HIV, said Anandi, to reach all areas of women's lives.

Luisa is the Monitoring and Evaluation Officer of ICW.

Maria de Bruyn

In Focus...

Disabilities and HIV and AIDS – How do human rights apply?

In a survey on HIV and AIDS and disability carried out for the World Bank in 2003, Nora Groce found that:

> *…HIV is a significant and almost wholly unrecognised problem among disabled people worldwide.*

In the past five years, more interventions have been developed regarding HIV and other STIs for people living with disabilities, but this diverse population is among the most marginalised regarding HIV and AIDS work. Over the past five years, incorporation of human rights principles into HIV and AIDS-related work has also progressed. It is now time to create the linkages between the two areas.

There are several internationally recognised human rights that directly apply to the development of interventions for people with disability. The **right to be free from discrimination** immediately springs to mind and this is now reinforced by the newly adopted UN Convention on the Rights of Persons with Disabilities, which says:

> *…State parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.*

More specifically, the Convention demands that States:

> *…provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.*

To respect, promote and fulfil this **right to health and healthcare**, it is vital that persons with disabilities receive information and education about HIV, other STIs, and other issues of sexual and reproductive health (SRH). For some groups, this requires the production of special materials and training of specialised providers and allocations for these are often missing from HIV and AIDS and SRH budgets. Research in the disability field has led to improvements in communication methods and aids that governmental and non-governmental programmes should incorporate, so that persons with disabilities are in the position to enjoy their **right to the benefits of scientific progress**.

...it is now time to create the linkages...

...healthcare providers often neglect discussions about family planning with women with disabilities...

Studies in various places have shown that persons with disabilities are at high risk of verbal, physical and sexual violence; one study in the USA showed that women with disabilities suffered abuse for longer periods of time than non-disabled women. In addition, healthcare providers often neglect discussions about family planning with women with disabilities and they may particularly lack access to contraceptives, if they suffer from spinal cord injuries or other physical infirmities. As a consequence, women face unwanted HIV and STI infections, as well as unwanted pregnancies. The **right to personal security, to be free from inhuman treatment, and to decide whether and when to have children** all demand that people with disabilities also have effective access to services for survivors of violence, including post-exposure prophylaxis (PEP), emergency contraception, safe legal abortion, psychological assistance and legal aid.

Maria is a Senior Advisor at Ipas.

Ida Susser

Reflections…

Women in the global HIV and AIDS arena

An ongoing struggle for representation and participation

Since the mid-1980s, researchers and grassroots organisers have been calling attention to the social and political context of AIDS, and to the specific situation of women struggling to protect themselves, but with scant effect. The sharp critiques of the early period could be repeated and expanded today with no loss of cogency or point. In February 2008, a *New York Times* editorial lamented '*a new surge*' in AIDS infections among young men in New York City, leading the Executive Director of the New York City Civil Liberties Union, to write a letter asking pointedly why only teenage boys were discussed: 48 percent of the increase was in teenage girls[1]. Why are women so invisible?

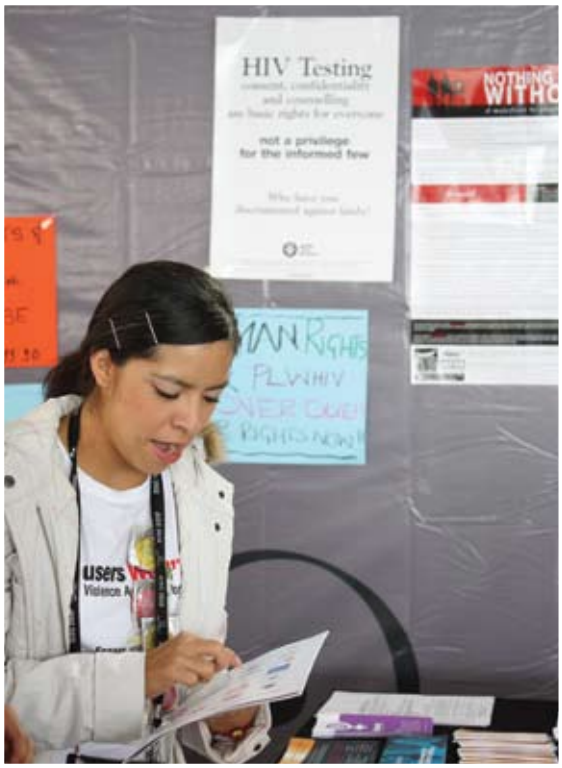
Not only was women's collective action not widely acknowledged or supported, but women's particular vulnerability to AIDS worldwide frequently went unrecognised. One major reason often given for overlooking the situation of women was that men were at the centre of the Western epidemic. In the United States, initial estimates suggested that positive men outnumbered women by about 10:1[2]. However, while all members of minority groups in the United States were three times more likely to have AIDS, than Whites, minority women were proportionately more at risk than men from minority groups. A Black woman was 13 times more likely to have AIDS, than a White woman and a Latino woman was 9 times more likely[3]. At the 2008 International AIDS Conference in Mexico City, twenty years later, in a report entitled, *Left Behind: Black America: A Neglected Priority in the Global AIDS Epidemic*, the Black AIDS Institute, noted that in the United States,

> *…AIDS remains the leading cause of death among Black women between 25-35years and the second leading cause of death in Black men between 35-44 years of age.*

The neglect of women in the United States from the early 1980s on, and actually as a result of this, of women internationally, points to a potent combination of racism and sexism.

History of women's struggles for representation in the global arena

The international recognition of the feminisation of HIV and AIDS has been both temporary and erratic. Indeed, the current political climate leaves little assurance that women's demands for protection, care, and treatment will progress in any concerted fashion in the coming years. While much attention has been paid to maternal transmission of the virus, the protection of women from infection has been less considered.



In 1990 at the San Francisco International AIDS Society Conference, plenary speakers Mindy Fullilove and Helen Rodriguez-Trias both articulately raised the issues of women's subordination. The Women's Caucus of the International AIDS Society was formed at this meeting. The 1992 International AIDS Conference was held in

…women's particular vulnerability to AIDS worldwide frequently went unrecognised…

Amsterdam after people refused to accept a conference proposed for Boston, due to US restrictions on allowing people living with HIV to enter the US. The decision was made rather late, which left little preparation time. Jonathan Mann, co-chair of the conference, was adamant that human rights and community participation – especially including people living with HIV – would be a key theme of the conference.

At that time, a group of women living with HIV in the Netherlands wanted to establish connections with other HIV positive women around the world. The Women's Caucus of the International AIDS Society and members of ACT UP The Netherlands proposed holding a pre-conference meeting that would unite positive women and help prepare them for navigating the conference. Fifty-six women from 27 countries attended this initial event and over the years ICW came to represent an extremely central group of women activists. As a result of this history of women's activism, a plenary at the 1994 Yokohama International AIDS Society Conference focused on '*Methods Women can Use*'[4].

In Durban, during 2000, at the International AIDS Conference, Geeta Rao Gupta gave a plenary speech concerned with women and AIDS. This was the first conference to be held in the global South. To enter the scientific conference required a hefty registration payment. Community-based women leaders and global advocates collaborated to create a forum parallel to the Durban conference that would be open to the public. '*Women at Durban*', as this initiative would come to be called, highlighted the need for open forums where community members could engage the International AIDS Conferences and led to the initiation of '*Women at Barcelona*' and '*Mujeres Adelante*' at the subsequent International AIDS Conference in Barcelona, Spain. '*Women at Barcelona*' was organised to bring together advocates and researchers on women and HIV at the conference. Organised by Creacion Positiva in Barcelona, '*Mujeres Adelante*' was a parallel forum, open to the public, which focused on the engagement of local community women living with HIV. '*Women at Barcelona*' and '*Mujeres Adelante*' staged a march at the closing ceremony to highlight their frustration with the neglect of issues important to women in the AIDS response, with chants, such as '*Women's health is world health*'. The difficulties for women to be heard in the conference persisted.

Together, these initiatives set the stage for the International AIDS Society to incorporate a forum at the International AIDS Conferences that would be open and available to local community members and conference delegates alike. The Global Village became institutionalised at the International AIDS Conference in Bangkok, Thailand, where the Thai Women and AIDS Task Force set forth a feminist platform.

...the protection of women from infection has been less considered...

At the 2002 Barcelona International AIDS Conference, the Women's Caucus of the International AIDS Society and ICW under the auspices of '*Women at Barcelona*' convened to draw up a set of principles for the health rights of women and girls, which became the *Barcelona Bill of Rights*. The Barcelona Bill of Rights, which included the controversial right to abortion, among such issues as rights to land and inheritance, was reiterated and carried forward at the 2004 Bangkok International AIDS Society Conference. The ATHENA Network was formed after Bangkok to connect feminist, human rights, and AIDS networks in global activism. Building from this history, ATHENA, ICW, the Blueprint Coalition, and Voices of Positive Women joined to convene the inaugural Women's Networking Zone in the Global Village of the 2006 International AIDS Conference in Toronto. Since that time, a Women's Networking Zone has been designated at international AIDS meetings, and panels related to women's claims and women's marches have been organised[5].

...to make sure the priorities of HIV positive women from Mexico and the region were represented...

Women's participation and representation in the global arena today

In discussing plans for sessions on gender at the 2008 International AIDS Conference in Mexico City, it was recognised that men who have sex with men (MSMs) were an extremely important risk group for Latin America and themselves highly stigmatised. However, at the same time, HIV positive women in Mexico City were struggling for representation on the planning panels. One of the problems raised by organisers was that most of the women did not speak English. Among the positive men in Latin America, English-speaking professionals could represent the

concerns of MSMs. But, it was suggested, most positive women were poorer and less educated than the men. In the end, Violeta Ross, who has a graduate degree in anthropology and is a member of ICW from Bolivia, as well as Patricia Perez, a founding member of ICW, spoke eloquently at the 2008 International AIDS Conference. In addition, one plenary paper was allotted to review the issues of gender and the vulnerability of women and girls, and another reviewed and represented the experiences and activism of women sex workers. A special request was added to the call for abstracts asking researchers to specify whether or not their data was detailed by gender. The controversies concerning the representation of gender and the voices of positive women highlighted the ongoing struggles, even in the most enlightened precincts, for women and girls to combat erasure of their needs for prevention, treatment, fertility, and sexuality with respect to HIV and AIDS.

In Mexico City women's issues did get a real place – there were packed sessions on breastfeeding, fertility and desire among positive women, and gender-sensitive discussions about micro-finance programmes, sex workers, medical male circumcision and inheritance laws. Many people were heard to say things like '*These meetings were really good on women's issues*' or '*there was a real change in the programme this year, we found so many panels of relevance to women'*.

These major shifts were the result of many years of work on the part of women's advocacy organisations, which were brought together under the ATHENA Network. In Toronto at the 2006 International AIDS Conference, there were no panels on breastfeeding, few papers on fertility, desire or women's perspectives on circumcision, sex work, harm reduction or other issues. Women's voices, disappointed with their erasure, were highlighted by the women and girls march organised by the Blueprint Coalition with ATHENA and other partners.[6] As a result, ATHENA together with ICW, Blueprint, and others, with considerable support and leadership from the World YWCA worked to remedy the situation from the ground up.

In 2007, Blueprint and ATHENA analysed the abstracts accepted at the 4th IAS Conference on HIV Pathogenesis, Treatment and Prevention in Sydney and found major gender inequities. Less than 20% of the abstracts addressed women's issues at all and most of these were concerned with mother-to-child transmission.[7]

To remedy this situation, a coalition of groups worked to nominate women's advocates for the initial Mexico planning committees. Members supportive of women's issues were appointed to the Community Programming Committee, Leadership Programming Committee and Scientific Programming Committee, and we worked to make sure that the abstract categories and programme descriptions would incorporate women's issues. Advocates for women also collaborated with other conference planners to include broader social justice categories, such as war, violence, globalization and migration that incorporate women's concerns. This ongoing work was reflected in the transformation of the Mexico Programme, which included significant contributions on issues crucial to all women, including women living with AIDS, commented on internationally.

...women's perspectives were heard loud and clear...

Further, ATHENA representatives strove to make sure the priorities of HIV positive women from Mexico and the region were represented throughout the main Conference programme, as well as in the Global Village. ATHENA formed a consortium with Balance Promoción para el Desarrollo y Juventud; Colectivo Sol; ICW Global; ICW Latina; and Mexicanas Positivas Frente a la Vida under the name '*Alliance for Gender Justice at AIDS 2008*' to create a Women's Networking Zone, building from the history of '*Women at Durban*' in 2002, and to lead a women's rally and march to the Zocalo in Mexico City.

As we have seen from the 2008 International AIDS Conference in Mexico City, the struggles for participation and representation continue – yet, women's organisations have pushed forward. Women's perspectives were heard loud and clear at the Mexico City Conference, which represented one more step forward in the struggle for representation of women's issues in the global arena.

FOOTNOTES:

1. Lieberman, D. 2008. 'Letter to the Editor'. In: *New York Times*, January 22, 2008.
2. Sabatier, R. 1989. *AIDS and the Third World*. Philadelphia: The Panos Institute, in association with The Norwegian Red Cross.
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5. Susser, I. 2007. 'Women and AIDS in the Second Millennium'. In: *Women Studies Quarterly*; 35(1,2):336-344.
6. Susser, I. 2007. 'Women and AIDS in the Second Millennium'. In: *Women Studies Quarterly*; 35(1,2):336-344.
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Jacqui Patterson

In Focus...

Invisibility and neglect

The session *Where are the voices of lesbian women?* raised issues that should be under greater consideration by the HIV and AIDS, as well as the women's movements.

It is very ironic, in fact, that in the early days, and to some extent still today, people equate feminism with lesbianism, yet from the discussion lesbians often feel invisible and neglected in the agenda of the women's rights community. As HIV and AIDS and women's rights movements we need to do a better job at incorporating issues of violence against lesbian, transgendered and bisexual women, as well as acknowledging and addressing the reality of HIV positive lesbians, transgendered and bisexual women.

Women of Color United facilitated a session on race, ethnicity, and indigeneity and impact on HIV and AIDS. This discussion yielded a sense of invisibility and neglect by women, whose very identity as racial, ethnic, and indigenous minority group members place them at heightened risk for HIV and violence. Women reflected that to the extent that race/ethnicity/indigeneity is acknowledged, it is usually in a way which pathologises, rather than addresses, the injustices these groups face; and how this impacts their environment, access to resources, culture, etc. The group agreed there needed to be more unity between women in racial, ethnic, and indigenous '*minority*' groups in the global south and global north for sharing of experiences and strategies, as well as to build political power to call on duty bearers to remove barriers to equal rights.

...people equate feminism with lesbianism, yet ... lesbian often feel invisible and neglected in the agenda of the women's rights community...

Jacqui is the Coordinator of Women of Color United.

Points well made...

Comment: We started listening to the voices and realities…

The International AIDS Conference (IAC) is as much a dynamic, exciting, and knowledge-sharing, as an intimidating and, at times, confusing space. The incredible opportunity I had to give a plenary input, to advocate for, and to put on the agenda the voices and issues affecting us, as young people, especially young women, to a room filled with decision makers and key analysts; and to provide contributions and ideas for an effective response based on our realities with respect to HIV – was very impacting and empowering. It was great to see the issues related to young women's leadership acquire more relevance.

I think that in the way we started listening to the voices and realities of those, who face the effects of AIDS and are most vulnerable, and as we start incorporating this into our actions for solutions, as well as our work language, we are able to have a clearer vision of what is at stake, and how we need to respond to the HIV and AIDS pandemics.

The real challenge, however, is what we are going to do when we go back home. If the IAC has implied a change in our actions, than we are to apply some of what we have learned. For me, one of the greatest benefits of my IAC experience was to see the solidarity, networking and community integration on the issues surrounding HIV, instead of the individualism so characteristic of the local level, and by our country authorities. In my opinion, women demonstrated the ideal response, as various other population groups, such as young people, did – together, integrated, and taking leadership, not just demanding it. I wish more of the political woman leaders would take a stand and sum up to our common efforts.

Already before this IAC and certainly after it, I think that issues of young women's leadership are on the discussion table, but still they are not fully on the implementation table yet. It would have been great to have more of the caucus activities – that were so characteristic of the women's networking zone in the global village – in the main conference.

The conference told us that women are vulnerable, due to many social norms, human rights violations, and various forms of violence; and that methods of HIV prevention are improving for us. While there is much consensus on women taking the lead on women issues, not much was emphasised on mainstreaming of women's issues through the array of actions surrounding HIV and AIDS. The conference further told us that we are at the centre point; that feminisation is still ongoing; and that there is more to be done. Yet, for me, what fell off the table in the main conference was best practices and in-depth analysis of solutions, and of where we need to target our efforts from now on.

Elisabet Fadul, Coordinadora General, Red Dominicana por los Derechos de los y las Jovenes D-Jovenes / Dominican Republic

Louise Binder

Reflections...

Quite a profound retrenchment

Dashed hopes for real change in the impact of HIV on women

I have been to a number of these conferences, and certainly in the early conferences, it was almost as though women were not involved in this epidemic in any way.

We were not seen as being impacted; we were not seen as doing the work; we were really invisible. This started to change with some satellite sessions about women's issues, but again these sessions were kept discreet – away from the main part of the conference. I think that the conference, in which we had the greatest visibility, was the conference in Toronto – where we had the first women's march that was an authorised march; where we had women's speakers early in the programme, and were part of the main conference and plenaries.

After the pinnacle, at Toronto, I had very high hopes that this was a real change in the understanding of the impact of HIV globally on women, and that, therefore, women would become an integral part of the conference, going forward. What I sadly see here in Mexico, is that there seems to be quite a profound retrenchment from that position. We are being relegated to satellite sessions, and a two day summit of our own, prior to the conference, and now we have a women's plenary at the very end of the whole conference.

...a real retrenchment from the position of weaving us into the whole fabric of this pandemic...

I see a real retrenchment from the position of weaving us into the whole fabric of this epidemic. And, in my point of view, that is a real tragedy, because the numbers of HIV infection among women are not decreasing at all, but instead the numbers are still climbing. I just don't think that suddenly women should be back to begging to be understood as 50 percent of this epidemic – and it seems as though we are really back there.

Louise Binder, Blueprint, Canada.

Calls for condoms

Many '*global villagers*' engaged in a wide range of challenging and interesting dialogues, engagements, and interactions inside the tent, while outside a number of '*calls*' were made by young people and their allies.

Highlighting that 50% of all new HIV infection are among young people, calls were made for condom use by a group of young people, while at the same time another group of young people calling for abstinence and '*not sleeping around*', tried to enter the '*village*'.

While most would see this as contradicting messages fuelling the HIV pandemic among people, this could also be seen as just a '*difference in prevention choices*' – with two groups of young people advocating for their '*choice*'. However, considering the high risk of HIV infection among people and prevailing challenges, including '*moralistic*' approaches to HIV prevention, advocating for abstinence in front of the Global Village of the 2008 AIDS conference was received by many as contradicting the sentiment of the conference.

So, while there are '*choices*' for young people, there is also the need to provide factual information about HIV prevention, and to ensure that promoted HIV prevention strategies are evidence-based – and evidence shows that condoms reduce the risk of HIV infection is a fact.

Cynthia Rothschild

Reflections…

The L Word and the G Word

There must have been 500 workshops at the International AIDS Conference that have *'sexuality'* in the title or in the tiny, almost illegible conference programme descriptions. Back to back, one would have to be here for a week to attend them all. But I'm still left with the feeling that something is missing. Maybe, more important than that frame is, *who* is missing, whose lives are somehow overlooked and rendered invisible, amidst the rich discussions taking place?

I'm wondering now about lesbians (and the epidemiologically-driven, but still rather flat term *'Women who have Sex with Women'* [WSW]). I don't mean '*lesbians are missing'* in a simple sense, because, as is the case since the inception of these AIDS conferences, we are consistently here, doing amazing work. But I still have questions about our lack of visibility as activists, as defenders of HIV-related rights, and as subjects of epidemiological inquiry. On the whole, we are seen more as *individuals* and not as a collective movement, and we are really quite absent from public health or human rights focus. In a cynical moment, I'm reminded of how little this discussion has advanced from the very early 1990s, when the U.S. Centers for Disease Control, if memory serves me correctly, claimed that a lesbian was someone who had not had sex with a man in 13 years. Fifteen years later and I'm still trying to figure that out. But I digress….

First, let me pay homage to those who have preceded me in these AIDS Conference spaces, and in first naming this critique. There are many lesbians who have organised at IAC events, and who have had some of these same concerns, for close to two decades. So what's changed? I think while the details may have shifted, the overall situation might be similar now to what it was years ago: seems there are two fundamental sets of questions – one about representation in conference proceedings, and the other set, in relation to ongoing lesbian and HIV advocacy and movement concerns.

Lesbians and '*lesbian issues'* could and should be a part of so many discussions in the venue. And yet, they, and we, are not, or, lest I be too cynical, we are not with *regularity*. We, and our concerns, are a sporadic addition,

…left with the feeling that something is missing…

an occasional bright light amidst the dark mood lighting in the session rooms and amidst the lovely frenetic chaos of the Global Village.

Let me start with two of the recent 2008 IAC bright lights:

There was a great lesbian/WSW session this week in the '*Hot Topics Zone'* (an area of the Global Village), where people from lots of different backgrounds and sexual orientations came together to strategise, to talk about sex, desire, violations, invisibility, movement building, the need for data on lesbians and HIV transmissions, and the need for advocacy at upcoming AIDS meetings. Possibly the youngest participant in this discussion was a fabulous woman – she was 14, and she spoke so passionately and earnestly about her sister, who is a lesbian, and who faces discrimination that, as our friend noted, made no sense. Exactly! Well, she got a much deserved round of applause from our group after her comment – a sweet, simple moment that was both moving and politically charged.

The other bright light occurred in a large session on violence against women, where an activist from the group Gays and Lesbians of Zimbabwe, made a great contribution as panellist – she highlighted violence against lesbians and how advocacy on this issue is particularly complicated in the current Zimbabwe political climate. Add an important undercurrent: her activism takes place in a country, where the president has said that gays and lesbians are 'lower than dogs and pigs'. She did not go into a lot of detail, but for anyone reading about (or living) recent developments in that country's economic and political landscape, her words had great meaning.

Aside from my two bright lights, and the wonderful discussions I have had with many women here, there is a range of discussions where this same set of issues related to lesbians and HIV is not consistently raised. Here is one policy-related example: in the development of the UNAIDS Global Fund-related '*gender guidance'*, there have been difficult discussions about the meaning(s) of the term '*gender*', and how to maintain a focus on experiences and rights of women and girls, but also highlight the needs and concerns of gay men, MSM (including in a gender binary for a moment, just reverse the WSW from above), transgender people and men and boys.

Lesbians and gender now occupy a thorny position amidst a struggle that sadly reveals both sexism and homophobia within our social justice HIV universe: lesbians are central, in theory, to both sets of analyses. But, without the proper level of scientific and sociological inquiry, '*women and girls'* means heterosexual, and '*sexual minorities'* means men and transgender people. So there is a risk, again, of our lives and concerns remaining too peripheral to both areas, since they have been cleaved rather awkwardly in two. In short, lesbians are women; we may be, or have been, girls; we are considered to be '*sexual minority'* (a term I really don't like, by the way); and some of us are also transgender. So do we need our own UN-based '*gender guidance'*? I hope not. Can we expect the groups, who sought this gender separation to adequately focus on women and sexual orientation in both the further use of the guidance and on-ongoing programming? Hmmm. Not sure. Are there lessons these groups will learn, once the dust settles? Hmmm again.

...set of issues related to lesbians and HIV is not consistently raised.....

...reveals both sexism and homophobia within our social justice HIV universe...

Here is another example of the complicated ways in which '*gender*' is used or misused in HIV discourse and analysis: I heard a panellist, in a session focused on gender, say that '*MSM have stolen the gender agenda'*. Her implication, to my ear, was that gay men in particular have stolen the term itself and the discourse of gender in ways that limit, in her mind, the focus on the experiences of women and girls.

My primary point here is that saying that *any* agenda within the HIV universe is stealing from another is tricky business. Agenda grow with visibility from social

movement struggles, and from the lessons learned from real lived – and often discriminatory – experience. To imply that one group of marginalised people '*steals*' the spotlight from another is a very knotty tactic. We get nowhere by arguing that abortion rights advocacy '*steals from'* a women's rights agenda, or that an AIDS focus '*steals from*' a broad health agenda. Surely there must be a place, among all the discussion, to have the experiences of marginalised groups become or remain simultaneously visible? Surely there must be a way of explaining detailed experiences in ways that build, rather than tear apart alliances?

So here is one more age old public health and epidemiological question that links, or does not link (as the case may be) lesbians/WSW sex and HIV and AIDS: in short, can we or can't we? In terms of transmission of the HI virus in woman-to-woman sex, studies have said '*absolutely, women can transmit the virus to other women*' and alternatively, '*it's very unlikely*'. But overall, most studies do not even address the question. So where does that leave lesbians? One quick answer: at risk. The absolute invisibility of WSW and lesbians in discourse and study of transmission is also problematic, because sometimes it is a silence perpetuated by our own social movements; there is no reason why women's rights advocacy and '*sexual minority*' advocacy should not address women's same-sex transmission. Gender debates, whether at the IAC, or in other HIV-related discussions, must break open this silence.

The same is true in terms of violence against women, a central agenda in women's human rights advocacy. There is almost no '*evidence-based'* data about lesbians, violence and HIV. What we have is a set of disparate stories about lesbians and WSW who sleep with, or are raped by men and who then contract the HI virus. And we have stories about HIV positive lesbians who are targeted for abuses – physical, emotional and verbal – because of their real or perceived sexual orientation. Too little women's rights advocacy addresses these stories, these realities, just as too little human rights advocacy addresses lesbians as targets of state and community/family violence. In these instances, these are not failure of the UN system or of the medical establishment, but of our own advocacy communities.

We are not immune, if you can forgive the pun, to phobic responses from, and ignorance within, women's rights and human rights communities. This, really, is where the invisibility of lesbians live and experiences come full circle as cause and consequence of narrow health and social justice agendas.

Effective HIV prevention and

...ways in which 'gender' is used or misused in HIV discourse and analysis...

...we need better means of addressing these omissions...

effective human rights promotion require specificity, visibility and recognition, especially in our universe of text and words, and documents, and policies. This is the same universe where, whether or not marginalised groups are named might mean, access to, or denial of, resources, or, in certain instances, life and death. That may sound dramatic. But I believe it is accurate. And it is accurate for lesbians. So, where we are named, and where we are recognised as activists, as subjects of public health studies or as survivors of violence matters. Saying the L word and the G word out loud, in the conference programmes, in ongoing health study and political advocacy matters.

We need better means of addressing these omissions; we need allies to do their work, whether in research, production of scientific data, or human rights reporting. And in the interim, lesbians will continue speaking out, making demands, holding workshops and talking about sex, pleasure and desire amidst the whirl of AIDS organising. I look forward to watching, hearing and reading all of the above.

Cynthia is a sexual rights/LGBT/HIV & AIDS/feminist activist based in New York.

Special report

The impact of criminalisation on women and girls

Aziza Ahmed

Criminalisation of HIV transmission refers to the use of criminal law to address HIV transmission. Criminalisation of HIV and AIDS has taken two main forms – through HIV specific criminal transmission laws and through general criminal laws applied to HIV transmission. Some countries not only criminalise the transmission of HIV, but go so far as to criminalise exposure to HIV (even in cases where no actual transmission takes place). This article will highlight some of the main critiques of the criminalisation framework both generally and with specific regard to women and girls.

There are several general critiques of criminalisation laws. First, criminalisation increases stigma for people living with HIV and/or AIDS. The use of a criminal law framework to address the issue of HIV transmission contributes to an unfounded notion that HIV positive people intentionally and recklessly transmit HIV. Alongside the laws themselves, media hysteria and public discourse about people living with HIV and/or AIDS as criminals, will be further stigmatising.

Second, criminalisation laws are unclear and, therefore, will be left open to interpretation by misinformed courts. For example, how will consent play a part in determining guilt? Does one's knowledge of their HIV status have to be actual or can a person be found guilty of HIV transmission if they '*should have known*' they were guilty? This question leads us to the related issue of how high prevalence (and often marginalised) groups will interface with the law? Will members of marginalised groups, who are already marginalised by the law, now find themselves vulnerable to yet another form of criminal prosecution?

Women will have a more nuanced interaction with criminalisation of HIV. Firstly, such laws criminalise mother-to-child transmission of HIV. Thus, mothers are often being made into criminals for having HIV positive children in resource poor settings, where they would have no access to PMTCT.

Second, routine HIV testing of women leads to the assumption that women know their HIV status. If a woman does not disclose her HIV status to her partner, due to fear of violence, for example, her partner could use the law to blame her for infecting him with HIV. This point also speaks to men's greater access to legal services and greater legal literacy, which results in lopsided access to the '*protections*' awarded by the law.

Third, and related, the use of condoms is a potential defence for women prosecuted for transmitting HIV – however, women often are not in a position to negotiate condom use. It is unclear how the gendered dynamics of sex will play out in a courtroom, and if and how courts will take these factors into consideration.

> ...criminalisation laws are unclear and ... open to interpretation by misinformed courts...

Fourth, laws criminalising HIV transmission will be reinforced by already existing laws which discriminate based on sex and gender. For example, in countries, which do not acknowledge marital rape, women are always seen to have consented to sex with their husbands. In a country, where HIV transmission is criminalised and marital rape is not recognised, the husband could always use the defence of consent to defend himself against his wife.

Finally, putting women in jail has a grave impact on families. Women are the primary caretakers and providers for the majority of households. When women disappear, it is girls that will have to replace them with likely negative effects, such as dropping out of school. Putting women and mothers in jail also worsens the situation for orphans.

Criminalisation of HIV transmission does not forward a rights-based approach to public health. To the contrary, criminalisation of HIV transmission detracts from progress made to respect the rights of people living with HIV, and to end stigma and discrimination.

Aziza is from ICW.

Risa Cromer

In Focus...

Conflicting rights...

Reproduction in the social context

The radical spirit and intention of the session *Impact of AIDS on Human Development: Reproduction in the Social Context* is best captured through the bold and important messages of its panellists. *'I am HIV positive and want to have a baby – who can ask this question, and what does she need?'* – posed South African women's health advocate and nurse midwife, Marion Stevens, to the packed room. Stevens argued that current practices of stigma and discrimination against intending HIV positive mothers need to be replaced with choice-affirming guidelines that recognise that healthy babies come from healthy women.

Gracia Violeta Ross bravely put a face and story to this issue, gaining increased visibility within the international AIDS conference, by explaining:

> *…I am more than HIV. Its one part of me, and another part of me wants to be a mother...*

For Ross, a HIV positive Bolivian woman and AIDS activist, as well as an anthropologist, becoming pregnant is part of her political statement and personal identity. In a candid and generous speech, she shared her fears and desires about becoming a mother, as well as mapped the medical and social stigmatisation she both anticipates and regrets.

South African paediatrician and researcher, Ana Coutsoudis, asserted that for intending HIV positive mothers, like Violeta, and non-positive women alike, '*we need to bring back breastfeeding as a norm – it should never have been anything else*'. Her presentation critically addressed policy and misconceptions about breastfeeding and mother-to-child transmission, especially in contexts of high infant mortality (e.g. lack of access to clean water, such as in sub-Saharan Africa, is likely to kill infants through diarrhoea five times more frequently, than HIV and AIDS). In these contexts, exclusive breast feeding improves the chance of infant survival, as well as the child's chances of living HIV free. In environments with low threats to infant survival where formula-feeding would be recommended, Coutsoudis affirms the centrality of women's right to motherhood, regardless of HIV status:

> *…I feel that women should have the right to breastfeed in the first world and shouldn't have their kids taken away from them...*

...practices of stigma and discrimination ... need to be replaced with choice-affirming guidelines...

...affirms the centrality of women's right to motherhood, regardless of HIV status...

Through respective presentations on widowhood and property rights in India, Priya Nanda and Kousalya Periasamy, illustrate wider contexts in which HIV and AIDS, parenting and social reproduction are intimately, and politically, linked.

The wider lesson from these papers is that, in contexts of conflicting rights or claims, whether between women and their children, property owning husbands, in-laws, or community, supporting women's right to choose, own and negotiate their own futures ought to be the driving concern of interventions and community mobilisations against HIV and AIDS. Indeed, this panel convincingly demonstrated that not doing so will deepen the pandemic's devastation to the lives of women.

Risa is a Doctoral Student at the University of New York.

Nyaradzayi Gumbonzvanda, General Secretary, World YWCA

In my opinion...

Every action counts!

As we go to Vienna, we need a women's forum in Vienna. We need more spaces for women as speakers. We have some women as speakers, but we feel we could have a bit more, instead of kind of a $^{1}/_{3}$ principle. I know we have women scientists, women politicians and women caregivers, so in each of the segments in the plenary I think we could have a little bit more women.

I'm passionate about us reclaiming that HIV and AIDS is not just a statistical issue, it is about individual women, men, girls and boys, who wake up every morning looking forward to a bright day, to a day with dignity and respect and food, and to walk in the streets happily and to go about their lives, like everybody else. That is what I'm passionate about. To be able to reclaim back the discussion on HIV and AIDS as a human rights issue, as an equality issue, as a power issue, as a civility issue. That is what I am passionate about. That it is about people, it is not just about numbers.

I am frustrated and angry that, we know, after 25 years, we know what works. We know the struggles that communities are going through, and yet, the AIDS response tends to not prioritise putting resources to where it matters most. In a number of countries, if you look at the military budget, compared to the health budget, there are very little resources going to a primary health centre – for there to be the basic medicines, for there to be the basic minimum of healthcare personnel, who is adequately motivated, adequately funded, for them to provide the first line of support to communities. But you will find billions of dollars in military expenditure, and that makes me angry. Because the life we know now, which we can protect now, we are not giving that priority, we are giving priority to anticipated external threats. The second is that especially women and girls continue to live with so much violence and abuse. So much! Whether it's multiple rapes, which happen, or just battering, domestic violence, or female genital mutilation, or trafficking.

...it is about listening for action...

...providing space for voices in the structures of decision-making...

We have so many baskets of declarations, so many, whether it is CEDAW, the declaration of violence against women, a statement by these big leaders, but we don't see a real zero tolerance to violence in a concrete sense. There is a lot of impunity, a lot of impunity! In my country, Zimbabwe, we have just experienced, and are still experiencing, this violence, which was accompanied by a lot of violence against women and sexual abuse, but we have not heard in any real sense about prosecution of abuses, of violence. Yet, there is international and global attention to men negotiating power for themselves. Six men at the table talking about power to themselves, and not about providing adequate resources to healthcare, to education, to prosecution of these perpetrators of violence.

It is those contradictions that we always want to bring to their attention, but also the story that women are not just waiting by, and waiting for external action, for them to be able to give each other support and care. We know of many organisations, including the World YWCA, who in addition to their advocacy work, do protect

practical strategic operations and provide strategic services, whether this be shelter, or counselling; organisations providing legal aid services; organisations providing healthcare, discussing what are the options if nutrition is not available, what are the herbs one can use if you cannot access medicine. Communities are finding ways of finding a solution.

Our community is also one of people living with HIV. We need meaningful involvement, not just greater involvement, but real, meaningful involvement of people living with HIV and AIDS. And meaningful involvement is not just about numbers. It goes beyond the numbers of involved people living with HIV and AIDS. It is about space, providing space for voices in the structures of decision-making. It is about acting on the voices and issues raised by people living with HIV and AIDS. It is about listening, without judgment, and without stigma and stereotyping. It is listening with compassion and empathy, and not with pity, but with a caring approach. But also a listening, which allows to look for alternative solutions, without remaining with '*now that I have listened, and my heart is bleeding, so I can go home and sleep*' – it is about listening for action.

And for us that is very powerful, we are looking forward to this conference on the whole notion of '*Action Now*'. What is the content of that '*now*', and who is taking responsibility for monitoring that '*now*'? So for us, from the women's movement and the YWCA, we are saying that that '*now*' has to be '*yesterday*'. It is not about '*now*'. It is about things that should have been done previously.

We know how the virus is transmitted. That we know. This is about human relations. This is about personal responsibility, but it is also about collective action, and part of that collective action is what kind of information is available to communities? And, in sub-Saharan Africa, where HIV is shouldered mostly by women and girls, who are we targeting with our sexual reproductive health information? We need to do more with young people, and we need to do more with young people around prevention messages, in a way in which, we cannot just physically reach them, but reach the young people in a way that they listen. Most of our approaches with young women work in such a way that young women have been saying

> *…hey, if you are talking about young women, your four day workshops don't work. Can you set up a space, like a facebook for young women in HIV and AIDS? Where we can blog and talk, even if it is a secure space, or protected space, but which we can talk in a language, we would know whether this is cool or not. Can we use more modern technologies? Can you work more with mobile telephones? For passing some of the messages but also in a language, which young people find exciting and funky…*

…the answer is: more information and more inclusion…

Those are the words of young women. So, how do we reach young women, and young men?

There have been a number of programmes, which are school focused programmes, but they have also not been adequate in themselves. But in sub-Saharan Africa, there are so many young people, so many young women, who are out of school. And where there is a combination of poverty, and unemployment and exclusion – that is one area of prevention that we need to scale-up, that we need to be innovative about.

In this region, and in Asia, there are a lot of discussions around drug use, and we also need to say what are the messages, what are the issues around criminalisation. So when we are talking about drug use, there is a lot of stigma related to drug use, and for us working on women's issues, there is also an assumption that drug use is mostly masculine, that it is mostly men. We need to bring to the surface that there are also women who are drug injectors, and how can there be a facilitating environment for us to discuss those issues, without criminalising. There has to be a discussion around the criminalisation and the support mechanism that is around the discussion. So on your question of what do we have to do? The answer is: more information and more inclusion.

Every action counts, every positive action counts, and never personally judge, or stereotype. It all starts with each individual, and having a positive attitude.

Special report

Violence against women and HIV: Women won't wait!

Neelanjana Mukhia

Around the world today, women and girls in every community confront, on a daily basis, the devastating effects of gender inequality, violence and discrimination that continues to place them at risk of HIV infection. Not only does violence against women, in its myriad of forms, hinders the abilities of women and girls to control the circumstances and conditions of their sexual lives, it also increases their chances of contracting HIV.

On the flip side of this, while violence against women and girls can lead to HIV transmission, violence also follows HIV infection, as HIV positive women and girls become easy targets for discrimination, violence and other human rights violations. HIV positive women are also likely to be targeted for violence and other violations, because of additional layers of discrimination and stigma they face, because they are HIV positive. Gender inequality lies at the heart of each of these, negatively impacting on women's health, well-being, and rights.

THE WAITING MUST END

Though some progress has been made in the last year, national and global AIDS responses still have not comprehensively addressed this intersection. Instead, when they have looked at both pandemics, they have failed to capture the dangerous synergy of the interlinked crises that put the health, lives and rights of women and girls at risk.

Women's movements throughout the world have long advocated for concrete action to promote and protect the human rights of all women – including the rights to be free from violence, coercion, stigma and discrimination, and the right to achieve the highest attainable standard of health, including sexual and reproductive health. The HIV community has also worked to ensure the promotion and protection of rights, with the prioritisation of women's human rights, as a response to the gender-specific impact of the HIV epidemic on women and girls. However, this global standard is rarely translated into policy and practice. In the case of the links between violence against women and girls and HIV, this results in the failure in policy and an abrogation of governments' and donors' accountability to respect, protect and fulfil the human rights of all.

...gender inequality lies at the heart of each of these...

...to significantly increase the resources... for both epidemics...

WE ALREADY HAVE THE ANSWERS

One of the most effective strategies to address the intersection of gender-based violence against women and girls and HIV is to significantly increase the resources directed to gender-sensitive and human rights-based prevention, treatment, care and support – for both epidemics. Education, including general education, as well as comprehensive sexuality education, is a core feature of effective programming. In addition, training legal, healthcare and educational professionals to recognise and respond appropriately to the signs and symptoms of violence, is also an effective strategy.

Approaches that rest on the experiences of women and girls, encourage and engage their participation in decision-making, and emphasise the importance of changing community attitudes to counter gender inequality are key to an inclusive approach, with specific attention to women and girls who are HIV positive. In the end, it is imperative that governments, families and communities '*combat*' impunity for violence, eliminate discriminatory laws and ensure efforts to foster gender equality in order to comprehensively respond to both HIV and gender-based violence. As long as gender stereotypes lead to violence, or the threat thereof, people will be at risk of the negative spiral of gender inequality, gender-based violence and HIV.

A DANGEROUS AND DYSFUNCTIONAL SPLIT

Funding for programmes that focus on violence against women and girls in connection to HIV remains inadequate and inconsistent. Research, conducted as part of the **Women Won't Wait: End HIV & Violence Against Women. Now**. campaign[1], entitled *Show Us the Money: Is Violence against Women on the HIV&AIDS funding agenda?,* illustrates the lack of concerted funding efforts aimed at responding to the twin pandemics. In an era of increasing accountability, Show us the Money aims to hold donors responsible to basic health and human rights standards in their policies, programmes, and funding streams.

According to the report, whereas issues around violence against women may be acknowledged in HIV policy documents of major donors, such a focus is often absent from programming on the ground. HIV programme efforts rarely cite violence against women and girls as a major driver and consequence of the disease, nor measure its occurrence statistically. Separate funding streams for each create an ineffective and dysfunctional split in intervention efforts, which do little to address the root causes of either pandemic. Furthermore, it is almost impossible to track resources targeting their intersection, as none of these donors specifically track their programming for, and funding to, violence eradication efforts within their HIV and AIDS portfolios.

The **Women Won't Wait** campaign in its report *What Gets Measured Matters: 2008,* takes stock of significant changes, updates, or revisions to the policies, programmes, and funding streams of the major donors, as presented in *Show Us the Money*. It finds that -– whereas there are few bright spots in the donor spectrum – overall the programmes and financial allocations continue to marginalise gender equality and violence against women in their HIV and AIDS strategies. Not only does failure to track (i.e. measure) the end point of funds equal an inability to know where the funding has gone, but it also means that measuring impact is nearly impossible.

...changing attitudes to counter gender inequality are key to an inclusive approach...

FOOTNOTES:

1. For more information about the Women Wont Wait campaign, please contact info@womenwontwait.org.

Neelanjana is the International Women's Rights Policy and Campaign Coordinator of ActionAid.

Special report

Needs of HIV positive women for safe abortion care

Luisa Orza

WHY POSITIVE WOMEN ACCESS ABORTION CARE

> *When I lived with him, I got pregnant. I decided on my own to have the abortion and get sterilised at the same time at a hospital. I did that because I had the infection. Because… wasn't the baby in my body?* [Woman in Thailand]

HIV positive women may need abortion care for various reasons. Rates of violence against positive women are high; when sexual assault is involved and a woman cannot access emergency contraception, she may want to terminate a resulting unwanted pregnancy. HIV positive women may access abortion services, because they deliberately and thoughtfully choose not to have a(nother) child. Lack of access to appropriate contraceptives, and little or no control over decisions regarding childbearing, also leads to unintended and unwanted pregnancies.

Our research shows that women, who already have children, when they are diagnosed with HIV, may feel less desire to have more. HIV positive women have also chosen abortions, because of fears that pregnancy would lead to poor health or death, so rendering older children motherless; and for fear that babies might also contract HIV or be unhealthy or die soon after birth.

WHO has also noted that, although the available data is limited, HIV positive women appear to have higher risks of stillbirths and miscarriages, which may require post-abortion care. The increasing tendency of governments to criminalise HIV transmission may also cause some positive women to choose abortion, for fear of repercussions, if their child is born HIV positive.

> *…the doctors also found out I was pregnant. I did not want to have a child at this stage and requested the pregnancy be terminated. The doctors only agreed to the termination on condition that I consented to sterilisation. I had no option.* [Woman in South Africa]

…they deliberately and thoughtfully choose not to have a(nother) child…

COERCED STERILISATION AND ABORTION

However, HIV positive women have been denied safe abortion care or have had to agree to sterilisation in order to access abortion services. In other cases, HIV positive women have been forced or feel pressured by healthcare workers to have abortions. HIV positive women may '*choose*' to have an abortion, because they are misinformed about the possible impact of a pregnancy on their health and that of their child. Such misperceptions can be heightened by health workers, who promote a view that HIV positive women should not have children. Yet, HIV positive women have the right to have children and, given the right care, treatment and support, they generally can have healthy pregnancies and babies.

Positive women should never be pressured by their partners, families or health workers to have abortions. Coercion to be sterilised, or terminate a pregnancy, is a violation of our fundamental rights to unbiased healthcare, self-determination, to decide the number and spacing of our children, to freedom from gender-based discrimination, and to freedom from inhuman treatment.

According to the World Health Organisation:

> *...Ensuring that safe abortion is available and accessible to the full extent allowed by law to women living with HIV/AIDS who do not want to carry a pregnancy to term is essential to preserving their reproductive health...*

WHAT COULD ABORTION SERVICES OFFER HIV POSITIVE WOMEN?

Abortion should not be the recommended option for HIV positive pregnant women. Rather, information about safe abortion should form part of a holistic package of sexual and reproductive health (SRH) services, information and advice that includes family planning, sex education and counselling, post-abortion/-miscarriage care, and prevention of perinatal transmission. Unfortunately, comprehensive PMTCT services that focus on the health both of the

mother and the health of the child in equal balance before, during, and beyond pregnancy and birth are still rare.

In order to enhance abortion healthcare for HIV positive women, sexual and reproductive health services need to provide:

- Improved information about, and access to, preferably free, unbiased, legal, safe and confidential pregnancy, childbirth, and/or abortion services for HIV positive women.
- Better training and awareness raising for health workers to reduce the frequency of coerced abortion and sterilisation among HIV positive women.

In addition, it is essential that abortion care providers should provide:

- Non-discriminatory, non-judgemental advice and counselling pre- and post-abortion
- Further information and counselling about family planning methods, including emergency contraception
- Referrals to post-rape services (PEP for HIV negative women, legal assistance, shelter, protection)
- Information and advice about sexual and reproductive health and rights, including gender-based violence
- Information about HIV care, treatment and support services
- Referral to relevant HIV and SRH services, including VCT

...HIV positive women have been denied safe abortion care...

Luisa is the Monitoring and Evaluation Officer at ICW.

In Focus...

A structure of subordination...

Gender discrimination took lives long before the HIV epidemic. But if we are to overcome the challenges presented to us by the virus, we must begin to address the role that the subordination of women plays in its proliferation.

On a panel entitled *Emergency in an Emergency Situation* – which focused on factors (social and environmental) that continue to exacerbate the HIV epidemic in Southern Africa – medical anthropologist Ida Susser made it clear that

> *...healthy women are essential to healthy communities...*

while also boldly challenging the conventional conception of women as a '*vulnerable group*'. Citing South African examples, drawn from her extensive research in the region, Susser suggested two major factors contributing to the '*surge*' of HIV infections amongst the region's women.

First, she questioned South Africa's recent neo-liberal policies that have limited investment in healthcare and transportation, which, she posits, were aimed at immediate financial gain, failing to support the *'legitimate kinship systems'*, which have traditionally provided a support network for women. Second, Susser addressed the international concern of '*moral rhetoric*' and socially reinforced gender systems, which provide a structure of subordination. While she specifically discussed gender issues, as they pertain to South Africa, it is quite clear that consistent failures in terms of gender equality are globally evident, and certainly present a unique emergency within the global AIDS emergency situation.

...consistent failures in terms of gender equality ... present a unique emergency...

Jonah is a Youth Advocate at the IAC.

Risa Cromer

In Focus...

Women's rights equal women's lives...

To the dismay of one woman queuing to ask a question of the *Women's Rights Equal Women's Lives: Violence Against Women and HIV* panellists, the connection between gender-based violence and HIV and AIDS is not acknowledged within many aspects of the AIDS response.

Amused by the request to summarise the connections between violence and increased vulnerability to HIV and AIDS in a ten minute presentation, Charlotte Watts emphasised the many types of violence beyond sexual violence (often the sole focus of HIV and AIDS interventions) that increase vulnerability, including psychological and economic abuse by intimate partners; early sexual abuse; and risky partner behaviour.

Anna-Louise Crago, a sex worker advocate and researcher, argued that aggression from state authorities, unequal protection under the law, and coercive sterilisation, abortion and HIV testing from healthcare providers are often overlooked forms of violence. In a complimentary move, Bafana Khumalo, co-founder of Sonke Gender Justice and the One Man Can Campaign, deconstructed the use of '*culture*' and '*religion*' to mask and justify gender-based violence.

Equally important was the symposium's stress that HIV and AIDS is but one epidemic among many; panellists argued and illustrated how violence and poverty are also devastating epidemics and challenging realities co-operating in the lives of people at risk or living with HIV. Despite the many overlapping and connecting factors between these epidemics, Watts wisely pointed out how responses to the respective epidemics sometimes undermine the other. For example, the 'ABC' intervention in HIV prevention is undermined by gender-based violence in that coerced sex trumps efforts to remain abstinent, or be faithful, and challenges one's ability to negotiate condom use.

...HIV and AIDS is but one epidemic among many...

Risa is a Doctoral Student at the University of New York.

Comment: Growing interest in work with men...

The ATHENA-Sonke-MenEngage panel provided a platform for important discussions about how to engage men and boys in accelerating efforts to bring about gender equality. A growing body of research is increasingly showing that work with men can bring about real changes in men and boy's attitudes and practices, and can lead to improved outcomes in terms of condom usage, sexually transmitted infections, sexual and domestic violence, and support for gender equality.

The ATHENA-Sonke-MenEngage panel was one of only a few events at the conference that provided an opportunity to raise and debate questions about the growing interest in work with men. It served as an important opportunity to discuss the emerging strategies and principles guiding work with men, and to call for greater collaboration between activists working for women's rights and male allies working with men and boys for gender equality.

Dean Peacock, Sonke Gender Justice, South Africa

Anand Grover, Special Rapporteur on the Right to Health

In my opinion...

Emerging hot issues

I think that one of the main issues, which is very important now, is the issue of sex workers and the rights of sex workers, as opposed to sex workers being trafficked. There is a very strong lobby in the United States that includes a large number of '*so-called*' feminist groups, who now argue that any person who has sex for money has to be trafficked. And they have actually now, in their definition in the protocol on trafficking, that if you have sex for consideration of money, then it is determined to be sex trafficking.

It means that women, who are adults and entering sex work on their own volition, willingly and by consent, are considered to be trafficked. If trafficking is going to be adapted to mean that, then the law would take its course by the police arresting these people and taking them into custody, where they may be put into rehabilitation homes, as in India, where there are no facilities at all for women. That is one issue.

The other issue is that '*so-called*' normal women are being subjected to violence and that is not talked about. It is not an issue that is considered to be worthy to be talked about in the HIV world. That is a tragedy, because HIV is closely linked to violence, as is health. And if a woman becomes HIV positive, more violence ensues, which I think the movement has to take up. And unfortunately, I don't see it being taken up in the coming period for various reasons. It is just ignored. It is a very critical issue that has to be addressed with respect to women's right to health and prevention against HIV, and the consequences of HIV that are being burdened upon women. The result is that people are dying.

...violence ... not an issue that is considered to be worthy to be talked about in the HIV world...

As Special Rapporteur, I am not going to decide on my own what should be the priorities. I think there has been a large number of developments on the issues of HIV and health and human rights, not only because the international humanitarian and UN organisations recognise the rights of marginalised groups, but also, because of the community empowerment and the way that the HIV movement has been mobilised. It is very important to assimilate those lessons, which I

propose to do. Access to treatment will be one of the priorities, not only limited to HIV treatment, but broadening out to the diseases, which impact on HIV.

Another priority will be the deployment of resources for health, not only HIV, but also other areas, like the primary health infrastructure. Similarly, I will focus on the deployment of resources for, and prioritising, the marginalised groups' issues, including MSM and sex workers issues. Not to be seen in isolation, I will also focus on the particular role and position, women and children occupy. These are some of the issues that a rapporteur would need to take up in the next three years. I do not want to predetermine the agenda on my own basis. I think it is very important to actually have consultations with various groups to find out what they think. Having said this, I also want to cooperate with governments, who are trying to solve problems. It is important that a collaborative effort is embarked upon.

One of the other key issues, in the narrow sense, is expanding the agenda of HIV positive persons' groups. It is important to understand, that unlike other diseases, HIV has been able to develop a community empowerment, which has not been seen earlier at all. Because of this, ART had to be provided, because the moral issue became so important. That issue is going to be a big issue now in terms of sustainability. Now with the debate that is going on, the question is whether or not that is sustainability at a local level or sustainability globally. And it is not only about HIV anymore and whether or not you are spending too much on HIV. The question is around whether or not the deployment of resources is skewed. So the argument that is being posited is '*no*'. You are not providing enough money for the other diseases. When enough money for other diseases happens, then you can have a rational balancing out. All the health issues have to be taken together and the kitty has to be enlarged.

...another priority will be the deployment of resources for health...

It is the responsibility of the HIV movement to ensure that other diseases, primary care, and the health system get their due resources. And the question is whether or not the HIV positive persons' movement is going to take up other diseases, such as hepatitis and TB? This is going to test the HIV positive movement because, as I see it, if they don't take these issues up, it is going to take away the ground under their feet.

Ida Susser

In Focus...

Sex work is work and the workers are organised!

Elena Reynaga (co-authored with Anna Louise Crago) delivered the first plenary speech by a sex worker. *'We want sex work to be recognised as work'* said Reynaga. *'Sex workers are not the problem; we are part of the solution.'*

Starting with the historic Sonagachi project begun by women sex workers in Kolkata in the 1980s, Reynaga demonstrated that sex workers have organised, through their work, to protect themselves from AIDS. Sex workers in Kolkata have a 5.17% prevalence of HIV infection, while other cities in India, such as Mumbai, have HIV prevalence rates as high as 54%.

Sex workers have mobilised all over the world to overturn criminalisation, and to meet with the Global Fund and UNAIDS.

However, in spite of these major successes in international recognition, Reynaga pointed out, sex workers are subjected to violence through government anti-prostitution policies. In Cambodia, for example,

> *…anti-prostitution policies have been approved under great pressure from the U.S. – and now, as a result, sex workers are being arrested under the pretence that they are victims of slavery and trafficking…*

Ida is a Professor of Anthropology at the University of New York Graduate Center.

Special report
Who should decide…

Ximena Andion

*In Chile, women living with HIV and/or AIDS are forcibly sterilised, because the doctors **'decide'** that they shouldn't bear children… In Brazil, the State **'decides'** not to provide adequate sexual and reproductive services to HIV positive women in prison… In Mexico, hospitals and doctors **'decide'** to deny services to HIV positive women that are pregnant.*

Stories of women who face violations of their reproductive rights occur from South to North of the Latin America Region. In all of these cases, doctors, prison authorities, husbands or communities are speaking for the women, taking over decisions that affect women's bodies and lives. As Niza Picasso from ICW Latina says,

> *…they assume that we, as HIV positive women, don't have reproductive rights, because we have HIV...*

For a very long time, sexual and reproductive rights were mainly linked to HIV prevention. However, as Maria Antonieta Alcalde from IPPF affirms,

> *…today there is a greater recognition of the urgency of addressing the sexual and reproductive rights of women living with HIV...*

…necessary to translate these commitments into concrete actions…

According to UNAIDS, approximately 500,000 women are living with HIV in Latin America and the Caribbean. The majority of these women face violations of their sexual and reproductive rights. The international human rights treaties that have been ratified by most of the Latin American countries protect the right to reproductive autonomy, privacy, dignity, non-discrimination and equality. It is necessary to translate these commitments into concrete actions, to ensure that women are the ones making decisions that affect their bodies and lives.

Ximena is the International Advocacy Director of the Center for Reproductive Rights, USA.

Comment: To collectively be stronger…

I'm happy to be here, because I feel like there is a lot of focus on violence against women. In different groups, initiatives are starting to focus with more attention on what each other is doing. So, I think we have more ability to actually strengthen what we are individually doing to collectively be stronger in our response, and I'm interested in what may emerge from this. I'm hoping that we can have a conference in Africa next year that brings together the grassroots groups to share their experiences and models of responding to violence against women.

Anne-christine D'Adesky, PulseWire, USA

Ida Susser, Zena Stein and Marion Stevens

In Focus...

Child survival and reproduction in social context

Linda Richter's plenary demonstrated that a healthy mother is what is necessary for a healthy childhood. Richter reframed the question of child survival from a narrow focus on *'AIDS orphans'* to a broader understanding of the need to support poor families in the age of AIDS.

Families, Richter stated, are the best place for children to grow up and must be supported and strengthened. She pointed out that, far from neglecting children, families have stretched their efforts far beyond their resources to care for children with AIDS. A Botswana study documented that families spent 25% of their household budgets on each sick child. Because of this commitment to their children, families forego education and even food.

Orphanages are not the answer. According to Richter, they cost ten times as much to raise each child and, in addition, children lose emotional and kin support and do not survive as well as they do in families.

To address these overall challenges, Richter called for renewed programmes of *social protection*. She demonstrated clearly what has been a centrepiece of many critiques, since the1980s structural adjustment programmes, that without a strong government investment in the support of poor families and their children, we will not be able to address the needs of children in the AIDS epidemic.

By the end of Richter's presentation, it was obvious why our efforts through NGO's and microfinance, well-intentioned and crucial for minimal survival at the moment, cannot possibly make up for well-directed public investment in entitlements and social welfare for the population.

We might wonder, however, why Richter, throughout her presentation and in handouts, never addressed the issues of women and mothers, or detailed her analysis of families by gender. She talks of poverty, but we all know that it is women, who are the poorest all over the world.

In a panel, *Impact of AIDS on Human Development: Reproduction in Social Context*, organised by ATHENA members with the help of ICW and the World YWCA, where over 500 people crowded into a session room, Kousalya, an Indian widow who found that she was HIV positive, when her husband died seven months after their marriage, noted that, in India and elsewhere, many widows are both victimised and impoverished. After their husband dies, women may be exposed to family violence and, while their boy children may be taken away from them, their daughters are left to share their mother's poverty. However, like Kousalya herself, widows have begun to form strong and supportive networks, to go out to work and to speak for themselves.

...need to support poor families in the age of AIDS...

...begun to form strong and supportive networks...

We know that girl children have significantly different survival rates, than boy children. In a picture shown by Anna Coutsoudis, in her paper on breastfeeding, we saw a mother with twins, where the hospital had recommended, she breastfeed the boy and formula feed the girl. The boy thrived while the baby girl, clearly malnourished in the photo, died the following day.

Coutsoudis' main point,

sharply illustrated by the same photograph, was that breastfeeding promotes child survival. In countries with an infant mortality rate higher than 25 per 1000, exclusive breastfeeding saves babies' lives in the long term. Replacement feeding may eliminate the transmission of HIV only to increase the rates of death from diarrhoea and other diseases. Coutsoudis called for a return to the normalisation of exclusive breastfeeding, widely practised in most of the world, before the commercialisation of formula and baby cereals. She recommended that women in poor countries could exclusively breastfeed, with support for expressing and saving milk when they worked, even quickly boiling it to kill the virus. She suggested that, in light of all the advantages of breastfeeding, women in middle income countries should be allowed the option to nurse their babies using similar methods.

In the opening paper on this panel, Marion Stevens called for treatment guidelines for women of reproductive age. In reviewing how vertical transmission programmes aimed to treat mothers and their unborn, she showed how this has prized treatment for preventing transmission to children over treatment for mothers. At the same time, she outlined how there needs to be more explicit clarity on contraceptive options, and to affirm women's right to a choice to a healthy pregnancy, or a choice to terminate a pregnancy. Given that some 50% of pregnancies are unplanned, she suggested that there is a need for greater engagement on these issues, and noted how current prevention activities are negative, not life-affirming and essentially controlling. In being specific, she highlighted

...has prized treatment for preventing transmission to children over treatment to mothers...

treatment regimens and how, first time options of Evafirenz and Tenofovir are contra-indicated in pregnancy, and that a common response of health workers is to tell women not to get pregnant – noting that this was reminiscent of population control. Even if we don't have all the answers, she argued that it was important to start working towards guidelines for women of reproductive age, and map out the continuum of care, options and question marks.

Following Stevens' thoughtful and detailed discussion, Gracia Violeta Ross powerfully described her own experiences, which dramatically highlighted the very themes Stevens had raised. As an HIV positive woman from Bolivia, 31 years of age, Ross wants very much to have her own children. As a member of ICW, she is a highly informed and educated global activist and spokesperson for people living with HIV, and as she noted, expected to be a model of behaviour. Expecting widespread condemnation, she courageously announced that she wanted a baby, just like any other woman, and was having unprotected sex in the effort to conceive. In a discussion afterwards, Ross noted that she had explored every avenue and that since her viral load was undetectable, she felt that she was doing the right thing.

Ida is a Professor of Anthropology at the University of New York Graduate Center.

Daisy Deomampo

In Focus...

We are part of the solution

The voices of sex workers – among session presenters and attendees – were heard loud and clear

> *No somos el problema, somos parte de la solución. – We are not the problem; we are part of the solution.* [Maria Consuelo Raymundo, sex worker, RedTraSex, El Salvador]
>
> *Remember: nothing about us, without us.* [Rachel Watton, sex worker, Scarlet Alliance, Australia]

The voices of sex workers – among session presenters and attendees – were heard loud and clear at the session, *Prevention Programmes with Female Sex Workers*. While session presenters discussed a range of strategies and research findings regarding effective HIV prevention programming with female sex workers, perhaps the strongest messages came directly from sex workers, arguing for increased participation and representation in HIV prevention and research. Frustrated by pervasive attitudes that claim sex workers are primarily responsible for engaging in safer sex practices, without acknowledging that clients must equally share in the responsibility; that they are to be blamed for HIV transmission; and that they are viewed as the '*objects*' of research, rather than active participants in HIV prevention programming, female sex workers argued that it is time to acknowledge their hard work, their intelligence, and their contributions to HIV prevention.

The session opened with two researchers, who presented quantitative data on successful HIV prevention strategies among sex workers. Their work demonstrated how peer-led initiatives resulted in increased condom use and distribution in India; and long-term behaviour change among sex workers in Nigeria. This research, however, raised questions about the participation of sex workers themselves, and about the perception of sex workers as merely '*informants*', rather than participants in HIV prevention work. As one sex worker asserted

> *…we no longer want to be considered a 'risk group'… we want to be part of the work, not just informants…*

– prompting applause from many of her peers in the audience.

The most enlightening and inspiring presentations came from sex workers themselves. Maria Consuelo Raymundo, of El Salvador, and Rachel Watton, of Australia, each shared stories from their own experiences working

with other sex workers on HIV prevention. The success stories of their respective organisations – RedTraSex (abbreviation for Red de Trabajadores Sexuales, Network of Sex Workers) and Scarlet Alliance – demonstrate that communities of sex workers have the strength and power to '*fight*' stigma and discrimination on their own terms, and in their own voices. Sex workers in the audience heartily applauded the work of these women and their organisations, and as one sex worker commented:

> *…We are ready; we sex workers are those, who need to be at the forefront, working on HIV prevention and fighting discrimination… I congratulate you*!

Daisy is a Doctoral Student at the University of New York.

Kate Griffiths

In Focus...

Lesbians lost in the debate on *'gender'*

The debate over the meaning of *'gender'*, between a women's rights framework and comprehensive gender framework, in the forthcoming UNDP guidelines for national strategies, has been widely lamented for, at times, seeming to pit the needs and interests of *'sexual minorities'* against those of *'women'*.

The presentation by Patience Mandishona, as well as several comments from floor speakers, at the seminar *Women's Rights Equal Women's Lives: Violence Against Women and HIV*, suggested that this framing of the debate ignores the needs and experience of lesbians, bisexual women, and female-to-male transgendered persons, when it comes to HIV and AIDS.

Referring to what Human Rights Watch has described as a *'pattern of violence'* targeting lesbians in South Africa, Mandishona called to mind the brutal murders of Sizakele Sigasa, Salome Masooa, and Thokozane Qwabe, as well as the widely publicised gang rape and murder of South African soccer player and activist Eudy Simelane, which have all taken place in the last year, among countless other attacks against '*queer women*'. She then warned that the wave of violence is beginning to *'spread'* into Zimbabwe, where Mandishona works as an advocate for lesbian and bisexual women.

Her organisation, Gays and Lesbians of Zimbabwe, (GALZ), has a difficult task in its efforts to '*fight*' for gay, lesbian and bisexual equality, given that homosexuality is outlawed, and has been declared intolerable by President Robert Mugabe. President Mugabe has also commented that lesbian women and gay men are 'worse than dogs or pigs'. Mandishona argued that this level of stigma against lesbian and bisexual women increases their risk for violence, including sexual assault and rape, and consequently their exposure to HIV. This insight makes clear not only that the intersection of violence against women (VAW) and HIV and AIDS is of particular importance to lesbian and bisexual women, but also that the issues of empowerment of women and women's rights are ones not so easily separable from questions of rights for '*sexual minorities*' as it may at first appear.

...ignores the needs and experiences of lesbians, bisexual women, and female-to-male transgendered persons...

The path to ending violence against lesbian and bisexual women remains less apparent, given the two examples provided by Mandishona. While the need for legal reforms and protection for lesbians in Zimbabwe seems obvious, the South African example should give activists pause; the rights of lesbian and gay people to live free from discrimination is enshrined in the South African Constitution, and South Africa was the fifth country worldwide to legalise same-sex marriage – the first to do so in Africa.

Nevertheless, stigma and violence against lesbian women remain endemic in the country, suggesting that legal strategies may only be a starting point.

Kate is a Doctoral Student at the University of New York.

Comment: We are all part of the same movement…

I think we are going to see a greater and greater convergence of health and human rights with human rights and human development movements generally. If you think about the health threats to people today, they are increasingly going to involve things like bad air, bad water, global warming, climate change, and such. This converges with the increasing recognition in Social Epidemiology that it is not the thing you die of that you have to worry about. It is not the virus that infects you, but the conditions which created your vulnerability to that virus in the first place. It is recognising that those conditions are things like social inequality, gender inequality, economic inequality and the structural violence that turn those conditions of inequality into health outcomes. Those are, of course, the same kinds of problems that are exposing people to excessive vulnerability, because of lack of water and sanitation or crop failure and lack of food.

So, I think for those of us working in the health and human rights movement in AIDS, the question is how can we reach beyond, how can we do what we do to ensure that people living with HIV, and at risk of HIV, get what they need, to deal with the virus, while at the same time, we are trying to see where we are really working in concert, or should be working in concert, with people we never think about – such as people, who think about food supply, water, or violence. Because these are all really issues that are related to what we do, and we are all really part of the same movement.

Scott Burris, Professor of Law, Temple Law School, USA

Comment: To meet women's needs…

Women living with HIV in the Chinese society face a lot of discrimination. People will say that she was with different partners and so on. They might lose their job. People are still afraid to become infected. In Taiwan, if a house owner found out that people, or babies, are HIV positive, they will not rent the house to them, or even ask them to leave.

I was so interested in one of the sessions, because one speaker said they work with lawyers. My husband is a professor of tax law, not human rights law, and I have lots of friends who are lawyers, but I have never heard of lawyers working for women's rights and HIV and AIDS. When I go back, I will try and reach these lawyers, and ask them if they would like to do something for human rights and HIV and AIDS in Taiwan.

I think in the community, the people need to talk about this, I feel like we should do more things, not just education and promotion. It is very important to prevent, but we still need to do something to meet women's needs.

Ping Lee, YWCA, Taiwan

Comment: Violence against women…

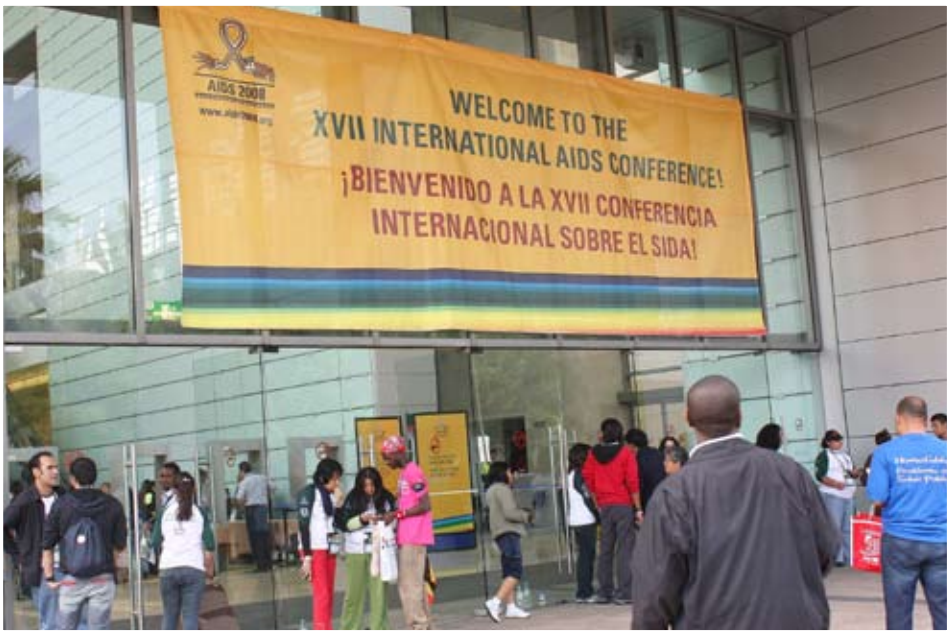
I would like to say that even if we find a medical solution, if we don't end violence against women, we will always have AIDS.

Martha Val, USA

Sue O'Sullivan

Reflections…
Taking stock…
Reflections on the Run

Now the conference is drawing to a close. We have worn ourselves out travelling back and forth between buildings, meetings, and searches for elusive friends and contacts. Carrying armfuls of materials and essential papers, we slide into fascinating sessions all over the Global Village, always heading back to the Women's Networking Zone, or our home base at the ICW booth. Dialogues, discussions and arguments have taken place in the Women's Networking Zone, and at the Positive People's Zone, among many others. It has been a long week and yet, it is flown by.



Now it is time to take stock. Among women what were the areas, which sparked the most controversy or interest in the Global Village? In our opinion, three areas have created the most informative, yet, contested discussions and debates. What is clear is that we do not always agree. No one can claim position as the only true feminist one. In the first issues of *Mujeres Adelante*, Anand Grover suggested that sex work would be an emerging issue at the conference. Other articles correctly identified other important issues for women, which included male circumcision, criminalisation, and violence against women. In fact, all these were the subject of ongoing discussion and debate. Nevertheless, we felt that there was a far greater realisation in Mexico that women, including HIV positive women, are part of all the proliferating '*identities*' claiming space in the Global Village – sex workers, IDUs, indigenous people, transgender women, and HIV positive people's networks. Steps were also taken to acknowledge that although lesbian women may not be particularly vulnerable to the sexual transmission of HIV through women-to-women sex, they may be IDUs, or sex workers, or occasionally have sex with men – all of which put them at risk of HIV transmission.

It became increasingly clear throughout the conference, that just because we are women, it does not necessarily follow that we agree on how to define, let alone solve, the hurdles women

…strong determination to work together for common goals, and to listen to others' positions, even when we disagree…

confront in the AIDS epidemic. But let us make it equally clear that there is a strong determination to work together for common goals, and to listen to others' positions, even when we disagree. We value hard tussles over important issues, which will place women, and HIV positive women, right at the centre of AIDS discourses.

On the '*hot topics*', the conference saw plenty of enthusiasm around plans to roll-out medical male circumcision projects. Women were divided on the issues, although our guess is that more feminist health activists were wary than not. But some were in favour. A UNDP women's health worker said in a Women's Networking Zone session,

> *...Why not? It might help and won't do any harm...*

But other women are more cautious. The data can be interpreted in different ways, and the numbers of separated foreskins needed in order to make a difference may be much more difficult to achieve, than is being suggested.

Lesson: What we all agreed with, is that male circumcision is a gender issue, and as with all gender issues, an analysis throws up complexities and contradictions. This is not a bad thing! A gender analysis which recognises complexity and context will enable us, as HIV positive activists, or women engaged in any number of ways

in work around HIV and AIDS, to develop a vital and applicable '*politics of gender*'.

Other '*hot topics*' included gender-based violence, or violence against women. *Mujeres Adelante* carried constructive articles on this subject at the very beginning of the conference. This was useful for women taking part in the unfolding workshops, dialogues and debates. In one session, women debated the meaning and uses of the words '*gender*' and '*women*', trying to settle on when and where to use these words. This session illustrated how important language is. Some grassroots participants reported that their members did not know what gender meant; while one woman made it clear that gender was a way of understanding the relationship between women and men. But, if you wanted to be specific about a need of, let us say, HIV positive women, you had to use the word '*woman*', or she might get lost somewhere behind the word '*gender*'. Someone else reminded us that gender is very fluid and does not refer only to '*women*' and '*men*'. What about transgendered people, she asked?

...the conference saw plenty of enthusiasm...

...a gender analysis which recognises complexity and context ... to develop a vital and applicable 'politics of gender'...

Lesson: A gender analysis is essential to an in-depth understanding of how women, men, transgendered, intersect, and others play out their lives – in all areas. It is informed by the intersection of all the other '*forces*' in our lives, including class, race and sexuality. We have to be specific about exactly who we mean when we talk about gender.

There are many other things we wanted to say, but we are running out of space and time. And we are certain that each participant in the Women's Networking Zone, and in our case, ICW, would want to raise different issues. We have not talked about criminalisation at all, which really featured strongly throughout the week, but we will have to leave that until the next time we join up.

Lesson: There is always too much to talk about and too little time at international AIDS conferences. But, we had a fine time trying!

Sue O'Sullivan and Luisa Orza have really enjoyed being correspondents for Mujeres Adelante!. Thank You!

Give females control

A group of about 50 women's rights activists gathered on Wednesday morning in front of the Media Centre to demand female condoms.

Interviewed by the media, Fiona Nicholson, TVEP, South Africa, pointed out that the failure to provide female condoms is nothing less than a human rights violation. Demanding explanations, she said:

> *…We know the HIV pandemic is a feminised pandemic, we know that women are more at risk of HIV infection, and we know that female condoms do prevent the risk of HIV infection. So, someone needs to explain why female condoms are not available. Someone needs to explain why women are denied their right to use female condoms...*

Using the tune of John Lennon's song *'Give peace a chance'*, everyone joined into lyrics of the Female Condom Song singing *'all we are saying, give females control; all we are saying, give condoms a chance'.*

Supported by Dance4Life, the singing, dancing and chanting continued, a female condom demonstration took place, and the halls of the conference centre were, for a short while, filled with the question *'where are the female condoms?'*…

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