

# Mujeres Adelante

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

## In Focus...

Ida Susser, Zena Stein and Marion Stevens

### Child survival and reproduction in social context

Linda Richter's plenary on Wednesday 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 programs of *social protection*. She demonstrated clearly what has been a centerpiece of many

critiques since the 1980s structural adjustment programs, 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 NGOs 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 handouts, never addressed the issues of women and mothers, or broke down 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*, organized by ATHENA members with the help of ICW and the WWYWCA, where over 500 people crowded into a session room, P 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 victimized and impoverished. After their husband dies they 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.

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 diarrhea and other diseases.

#### Whats inside:

**Special report:**  
Depriving women of support

**Feedback from the Global Village...**  
Opposing views

**News from the 'margins'...**  
Sexual pleasure and HIV prevention

**Women's realities...**  
Take seriously and affect change

**Women's Voices...**  
Need safe spaces first

**Regional voices...**  
Likely to criminalise women

Coutsoudis called for a return to the normalization of exclusive breastfeeding, widely practiced in most of the world before the commercialization of formula and baby cereals. She recommended that women in poor countries could exclusively breastfeed, with support for expressing milk and saving it 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 programs 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 of these issues, and noted how current prevention activities are negative, not life affirming and essentially

controlling. In being specific, she highlighted treatment regimens and how, first line 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 Violetta 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 behavior. 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.

## 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* and 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 condom?'...



## News from the Global Village...

### 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, making calls for abstinence and 'not sleeping around', tried to enter the 'village'.

While this 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.



## News from the margins... Kate Griffith

### Sexuality 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 prevention programming? What choices are available to HIV-positive women and men, who desire and intend to have children? The session on *Reproductive Health: Sexuality, Fertility and Desire* covered a range of these often overlooked themes in discussions around reproductive health and HIV.

The session opened with the theme of gender, power and sexuality within transactional sex in research presented by Joyce Wamoyi. Discussing a 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. For

many of Wamoyi's respondents, transactional sex represented a way for young women to 'equalize power in sexual relationships', signaling the importance of understanding gender and power issues associated with the practice.

Issues of pleasure and desire were also brought to the forefront of discussions around empowerment of women and HIV prevention. Tsitsi Beatrice Masvawure presented 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. 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 greatest risk of becoming infected with HIV 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 for women's pleasure, while recognizing that violence is an ever present danger.

But how do these findings translate into effective HIV prevention programming? In the case of Wamoyi's research in Tanzania, HIV interventions must train young women to incorporate safer sex 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. In order to effectively take up pleasure within HIV interventions, it is crucial that we understand the various ways in which pleasure is constructed, and not taken to be a self-evident experience.

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

## Women's Realities...

Sophie Dilmitis

# Women Take the Lead

Given the opportunity and properly guided, resourced and supported, I have seen the creativity and energy that young women have in playing a determining role in leadership around HIV. But how do we build young women leaders, who have just been told they are HIV positive, and create leaders?

### **The first step is to have a support system**

When I was diagnosed HIV positive, it was such a relief to be with people who find themselves in similar situations and who had experiences to share. These personal lessons learnt can make all the difference, for example how women coped when they were first diagnosed, and how they became emotionally stronger in order to deal with the adversity that many of us face when we fully disclose.

Young women need access to comprehensive information and support that assist dealing with the initial shock of receiving a positive diagnosis, as well as access to healthcare that can prolong their lives, enabling them to advocate and become leaders.

### **Having a vision and acting on it**

*...action without vision is pointless, vision without action is fruitless, but combined it leads to great things...* – Positive Development GNP+

Women need a source of inspiration, which most of the time is the urgency to advocate for a need, which is not being met. The realisation that challenges them is bigger than themselves, and the rewards that come from effecting change are for the betterment of communities. They need links

to groups, reducing the sense of isolation. Young women need organisations that are youth friendly and open minded.

### **Mentorship**

All effective leaders have people they can rely on for support – someone who has a wealth of knowledge, offers inspiration and who believes in the woman's ability to make a difference, encouraging her to take risks and to stretch herself.

### **Capacity building and sustainability**

Young and community women need information, skills, and training around their area of work, as well as supportive environments. Workshops and trainings should never be once-off events and should always be followed with necessary resources to further their leadership skills, allowing women to practically use skills they have been given.

### **Experiential learning**

It is vital that young and community women are given safe and nurturing spaces to develop their abilities, whilst developing their leadership skills through initial volunteer and leadership opportunities.

### **Mobilising resources**

Investing in young and community women's leadership is vital. Women cannot progress without financial support.

### **Understanding international processes and documents**

For young women to be taken seriously and effect change at a policy and national level they must have advocacy skills, enabling them to influence policies and

... programmes and policies must be designed so that they give a voice to young women...

programmes that directly affect them. For this to happen they need to be able to understand the process of policy change and have the ability to understand complex documents. If young women do not understand complex UN documents how are they to be meaningfully involved?

This takes me back to my point of capacity building – I cannot stress this enough! If you really want to put your money where your mouth is – this is what needs to happen. The *Meaningful Involvement* of young women may never be anything but tokenistic, unless it brings people to the table, who understand policy at an institutional level.

### **Passing on the baton**

It is crucial that leaders become mentors and pass on the baton of leadership to other young and community women. If you are invited to a meeting – take a young woman with you.

### **Last but not least – Involving Men**

Women know what will effect change; they just need support making it happen. If women, especially young women are to take action, and if we are to increase women's leadership, it is fundamental that men and boys be involved in the process. We need strong men – who will come along with us.

Changes must be made in response to a real need, and as a result of social dialogue, which includes the voices of young and HIV positive women. All programmes and policies must be designed so that they give a voice to young women.

*Sophie is the HIV and AIDS Coordinator of the World YWCA.*

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## Women's Voices...

Luisa Orza

# Women and HIV in Asia

HIV and AIDS continues to be described as a concentrated epidemic in Asia, with interventions focusing 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 laws 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 in general in a vulnerable position in many parts of the region. This vulnerability is reflected in increasing rates of HIV infection throughout the region, and in particular among women.

In the **Women's Networking Zone** today, 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 recognition that HIV transmission among women in the region mainly 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 don't feel themselves to be at risk. Interventions that focus on MSM, IDU, sex workers and their clients rarely acknowledge the risk that these behaviors pose to wives and partners, who tend to fall through the programmatic gaps.

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. However, for a woman, the speakers agreed, we need to start with women.

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 can't even speak to her husband about sex? And empowerment needs to go beyond HIV, said Anandi, to reach all areas of a woman's life.

*Luisa is the Monitoring and Evaluation Officer of ICW.*

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## UPCOMING EVENTS

### Thursday, 07 August 2008

#### **Breastfeeding and perinatal transmission of HIV**

12:30-14:30, poster THPE0259

HIV-1 transmission during pregnancy, delivery and breastfeeding

12:30-14:30, poster THPE0273

Qualitative insight of healthcare workers on breastfeeding education and practices of HIV-positive and HIV-negative women in Kabarole district, Uganda

12:30-14:30, poster THPE0275, Making formula feeding acceptable: reasons given by HIV non-breastfeeding mothers to avoid stigmatization in Cameroon

16:30-18:00, Session Room 5

Advances and Challenges: Reducing HIV Transmission to Infants

12:30-14:30, poster THPE0924

Ante-natal routine offer of testing and criminalisation of vertical transmission – infringements of women's – and children's rights

#### **Sterilization and abortion**

12:30-14:30, poster THPE0529

Reproductive health rights compromised: factors affecting access, choice and utilization of sexual reproductive health services for HIV positive women

#### **Lesbian women and HIV**

12:30-14:30, poster THPE0382

Evidence-informed and planned HIV prevention for LGBT (lesbian gay bisexual transgender) populations in Southern Africa, Latin America and Surinam

12:30-14:30, poster THPE0405

Integrating AIDS prevention into a Gay & Lesbian Film Festival

Sophie Pinkham

# Special report:

## HIV and women who inject drugs

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, they 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 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 HIV-positive.

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 fulfill 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 PMTCT is poor, even in countries that have declared universal access to PMTCT. At a satellite session on Sunday, Ruslan Malyuta of UNICEF explained that in St. Petersburg, where ART is relatively well-funded, only about 50% of pregnant 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.

Healthcare providers continue to stigmatize or reject women drug users, and few programs 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 unable to regain custody, when they come home. Around the world, many rehabilitation centers do not even

accept women, especially when they are pregnant or HIV-positive.

Meanwhile, there are all too few programs that give drug using women the support they need. One exception is *MAMA+*, a program for HIV-positive pregnant and parenting women, many of whom are drug users, presented by Anna Shapoval during a session on Saturday. Pioneered by Doctors of the World in Ukraine and Russia, *MAMA+* offers a wide spectrum of services, ranging from basic material assistance and counseling

**...women drug users often ... have nowhere to turn for help...**

to legal aid and referrals to ARV and drug treatment. Using a multi-disciplinary case management team and a personalized 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 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.

Because internalized 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*, composed 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.

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.

*Sophie is the Program Officer at the International Harm Reduction Development Program of the Open Society Institute.*

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## Regional Voices

### To Transmit or Not to Transmit

*Kate Griffiths*

Quoting the experience of one woman living with HIV in South Africa, advocate Michaela Clayton called upon the audience of Wednesday's seminar *To Transmit or Not to Transmit: Is That Really the Question? Criminalization of HIV Transmission*, to imagine the outcome of increased criminalization 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 testing, beat her until she miscarried, when her pregnancy was in its fourth month.

Some women's rights organizations call for legal penalties against such violent and abusive husbands for exposing their wives to HIV, 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 in Africa – are likely to further stigmatize and marginalize women living with HIV and

AIDS. They argued that existing laws are sufficient to prosecute abusive men, and suggested that laws which criminalize 'willful' transmission of HIV are actually likely to disproportionately criminalize women, as women are far more likely to be aware of their status than men.

Human rights lawyer and advocate, Richard Pearhouse, drew audience 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 criminalize various forms of 'willful' transmission. In two cases, in Sierra Leone and Cote d'Ivoire, the model has been adapted to explicitly target 'willful' transmission from mothers to their children, either in utero or through breast-feeding.

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

Elena Gonzales, Women's Rights and HIV & AIDS activist,  
part of Global Village Team

## In my opinion...

# Developing local capacity

One of the things that has been a challenge in developing the presence of the Global Village within the AIDS conference here in Mexico is that there has not been a sufficient commitment to building and developing local capacity and local partnerships. As we go forward I think the lack of local partnerships, and thus voice and representation, reduces the impact of having the conference here in Mexico. The development of the local community is not a priority, or a part of the governance of the Conference, there needs to be more of an effort made to 'translate' the conference to the local community, and similarly, for the IAS to get to know and understand the local dynamics. You can see this in the fact that the Federal government has been asked to partner with the Conference, but the Federal government is not engaging with the local City government for political reasons, so local Mexicans know virtually nothing about the conference and thus, cannot take advantage of it being here. In fact,

the federal government only sent the local HIV health officer to attend the conference, as they don't understand the interconnections and issues of the epidemic, especially with regards to women.

There are no banners in the city, and no local museums or institutions are allowed to host events – so the potential that exists by being here has been lost. The Mexican people are still not involved, as they have not been brought into the process. Hopefully this can change for Vienna. Developing local legitimacy, relating to local NGOs and local messages, would strengthen the conference and without it, when the office closes in September, there will be no way to continue to build from the Conference here in Mexico. If the IAS had understood things from a local perspective, I doubt they would have made some of the decisions they made.

It would have been wonderful if the IAS could have helped hold our government accountable to all the agreements that it has signed. Our

... there needs to be more of an effort made to 'translate' the conference to the local community...

President only spoke of tolerance, not respect, of scientists and doctors, not activists and community leaders, the IAS could use its presence to support more political demands for promoting and protecting the human rights of all Mexicans.

What we have seen is that the commitment to mentoring and capacitybuilding is no longer a priority, and the impact is huge within the women's movement. More and more it is First World activists, groups and skilled conference users that come over, but there is no commitment to developing local capacity, and this again creates a distance between the local community and the conference, and the relevance of the Conference to the host city. I think the conference has transformed from being about developing a worldwide 'movement' that is inclusive of all people, to being more exclusive. As the Conference becomes more 'polished', I think we are losing some very important opportunities. I hope as we move to Vienna in 2010 this can be addressed.

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