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More visible than ever before...

Looking Back on Vienna 2010

Kate Griffiths

The 18th annual International AIDS Society (IAS) Conference held this year in Vienna reflected both celebration of major accomplishments in the field of medical research and AIDS policy, and a somewhat apprehensive view of the future of HIV and AIDS research and policy amidst a global economic crisis and shifting donor priorities.

Held between July 18 and 23 at the Reed Messe Wien, AIDS 2010 gave members of the HIV and AIDS research and advocacy communities a window on the European epidemic, which in turn called attention to the criminalisation of sex work and drug use and the need for increased focus on human rights.

This rights focus culminated in '*The Vienna Declaration*'[1], a statement signed by more than 17,000 scientists, advocates and policy makers to date, which declares that '*policy should be based on science, not ideology*', and which calls for an end to the global '*War on Drugs*', arguing that existing drug policies are in many instances both unscientific and a source of human rights violations around the world. This declaration also coincides with a victory for health advocates in the United States, as a decades-old ban on federal funding for needle-exchange programmes has been rolled-back under the Obama administration.[2]

For advocates of a rights-based approach to HIV health

Mujeres Adelante
A NEWSLETTER ON WOMEN'S RIGHTS AND HIV

Editorial...

This fourth (and, for now, the last) issue in the series of special *ALQ/Mujeres Adelante* editions on women's rights and HIV looks back at the 2010 International AIDS Conference in Vienna and shares some of the conversations and highlights that transpired at the conference. Remaining true to our core question as to whether or not women's rights, realities and needs are indeed at the centre of the AIDS response, the various articles in this edition explore the extent to which women and women's rights, realities and needs were at the centre of discourse at Vienna 2010.

And while most contributors tend to agree that there has been progress in that human rights were '*more visible than ever before*' and '*present and alive in a large number of panels, workshops and satellites*', there is also the recognition that there are a number of remaining challenges, as well as continuing omissions, in our discourse and responses to women's rights and HIV, as '*women's needs and rights in many cases remain marginal to policy and research agendas*' and the progress made '*does not imply that the road ahead is an easy one*'.

Looking back at Vienna 2010, this edition introduces a '*snapshot*' exploring both the progress and the stagnation (as presented and discussed at the conference), continuously raising the question as to the adequacy of the AIDS response to women's rights, realities and needs.

One of '*highlights*' of the conference has been the release of the CAPRISA study results indicating a microbicide success, and the new and long-awaited opportunities these results present to women and women-controlled HIV prevention options. Welcomed with cheers and celebrated worldwide as '*a win for HIV prevention, women's rights and scientific discovery*', this '*success*' also initiated critical debates as to how to move forward and '*where to go from here*' to ensure that

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treatment, policy and research priorities, the declaration and the conference theme were a reflection of the increased emphasis on human rights as a critical framework for approaching health within the field, after a generation of advocacy toward that end, while at the same time an opportunity to reflect on a number of still-growing threats to rights-based policies and to people living with HIV.

…policy should be based on science, not ideology…

The conference theme '*Rights Here, Right Now*' was a welcome acknowledgement for advocates, community members and researchers who have long been focused on the intersections between women's rights, LGBTQ rights, prisoners rights, poor peoples' rights, and the rights of youth and effective HIV and AIDS policies. With '*rights*' as the unifying theme, once marginalised issues, such as the sterilisation and criminalisation of women with HIV, the rights of intravenous drug users, sex workers, and LGBTQ people, were more visible than ever before in the convention's main sessions, plenaries and workshops presenting the latest research. Speakers once relegated to '*the margins*' of past IAS conferences often made double appearances this year in the Women's Networking Zone, as well as in mainstream sessions inside the central convention hall. Speakers at main panels included rights advocates, such as Vuyiseka Dubula, General Secretary of the Treatment Action Campaign (TAC) in South Africa, Anya Sarang, President of the Andrey Rylkov Foundation for Health and Social Justice in Moscow, Russia, and Paula Akugizibwe of the AIDS and Rights Alliance for Southern Africa (ARASA). People living with HIV, women, young people, and those from the communities and nations *most affected* by HIV are speaking for themselves, in conference venues, and are at the centre of the debate.

…both unscientific and a source of human rights violations around the world…

In addition to this focus on human rights approaches to HIV and AIDS policy and treatment, rights advocates celebrated the major victories for the right to health of people living with HIV that have taken place since the 2008 IAS conference in Mexico City. Most notably, advocates cheered progress toward '*universal access*' to highly active antiretroviral therapy (HAART), with more than 5 million of those who need treatment now receiving it. This is in part due to the dramatic shift in South Africa's stance toward HAART since 2008.

In South Africa, home to one of the world's largest and most severe HIV and AIDS epidemics, AIDS policy under President Thabo Mbeki was clouded by denialism and austerity from the highest levels, with top government officials and many local service providers publicly disputing the scientific consensus that the human immunodeficiency virus (HIV) causes the collection of infections known as AIDS, and the resulting impact on the most economically and socially active section of South Africa's population, as well as high infant mortality in the country. Over the last three years, the policy has slowly shifted during transition to new leadership, with HAART first focused on the prevention of mother-to-child transmission, toward a policy of access for all people living HIV with CD4 counts below 200, and below 350 for pregnant women and those co-infected with tuberculosis.[3] This broader shift in policy and response has

the '*concept*' of new HIV prevention opportunities for women will become '*reality*' – in a timely and safe manner. While some argue that '*proof of concept is not enough to declare victory*', as '*stronger evidence*' is required and further '*validation is essential*', there are also questions raised as to '*how much protection is enough*' for women to truly benefit from these new opportunities and *when* HIV prevention for women will become reality. Underlying this debate is the call for microbicides '*to be made immediately available*' and the acknowledgement that '*while we continue the debate, women continue to be infected and die*'. Although quite contradictory at times, the common theme in this debate seems to be the request that '*research truly moves us onwards from where we are now*' and that women's prevention realities and needs are to be the focus of both the discourse and the way forward.

And as for stagnation and the realisation of how much remains the same, '*why the silence*' on sexual rights and '*where are the lesbians*' in the response to HIV continue to be questions raised again and again. The realities and needs of '*invisible sexualities*' are still not integrated into '*mainstream*' debates and discussions on women's rights and HIV, and thus continue to be under-represented in '*formal*' conference proceedings, as '*stigma continues to render invisible the sexualities of those most marginalised by gender bias and heteronormativity*'. Trans women were one of the many groups raising their anger and frustration about the neglect to integrate their specific realities and needs into research, policy and programming. And while the continuing invisibility and marginalisation greatly impact on the adequacy of the AIDS response, it also reflects the extent to which human rights are indeed at the centre of the discourse and response. And as long as trans women are not '*heard*' in the main sessions of a conference, and remain '*relegated to the Global Village and offered a stage to do drag shows*', we arguably fail to move forward in our '*rights-based*' approach to HIV.

Criminalisation in its various forms and its impact on HIV risks and related rights abuses, as well as the adequacy and effectiveness of the AIDS response in addressing and/or perpetuating the criminalisation, has been the centre of debate and advocacy for quite some time. Prevailing stigma, discrimination and other violations of rights on a person's (actual or perceived) HIV status; continuing judgement of peoples' sex and sexuality, sexual choices and desires; and the ongoing prejudices against and exclusion of the '*other*' and anyone perceived to be '*different*' are but a few of the realities that fuel the criminalisation, legally and socially, of sex, sexuality and HIV, and threaten human rights – both within and outside international conference proceedings.

'*Criminalisation*' was the topic of numerous formal, as well as informal sessions at Vienna 2010. Recognising that the persistent criminalisation of sex, sexuality and/or HIV not only undermines the effectiveness of the AIDS response, but also threatens human rights in the context of HIV and AIDS; the need to oppose both legislative trends and common

already had a dramatic impact on the lives of people living with HIV, with increased anecdotal reports of decreasing social stigma and increasing grassroots acceptance of HAART. The treatment is already having a dramatic and discernable impact on the number of children born with HIV, and is expected to reduce transmission rates in the general population.

In addition to this achievement for the global HIV and AIDS community, rights advocates – in particular, feminists – celebrated a major new research achievement which highlights both the importance of, and the need for, further scientific research that centres on the rights of women. IAS 2010 saw the announcement of study results demonstrating the partial effectiveness of Tenofovir Gel, the first preventative microbicide. The treatment, WHICH reduces HIV infection in women by at least 39%, can be applied vaginally as many as 12 hours prior to sex and up to 12 hours following sex.[4] Along with female condoms, which have been recently improved, availability of the Tenofovir gel would double the number of women-controlled methods for preventing transmission of HIV. This need for such methods is increasingly being recognised as researchers note the connections between gender-based violence, female disempowerment, unprotected sex and HIV transmission in the context of generalised epidemics.

…the need for, further scientific research that centres on the rights of women…

…increased emphasis on human rights as a critical framework for approaching health…

But, despite this progress towards human rights for all people living with HIV, voices for human rights, both from the dais and in the form of chanting, dancing and protest, warned of continued, serious threats to autonomy, health and security that are picking up steam worldwide.

WOMEN'S RIGHTS AND RISKS

Women's rights and HIV intersect in the realms of biology, social life, health policy and law. Despite increased global attention on the rights of women in recent years, women are still being disproportionately impacted by HIV and AIDS, and women's needs and rights in many cases remain marginal to policy and research agendas. This marginalisation was reflected in women's experiences shared in the Women's Networking Zone (WNZ) and Global Village, as well as at a number of main sessions inside the convention hall.

Women are at higher risk of transmission; research suggests that in addition to biological vulnerability to the disease, it is women's social vulnerability that increases their risks. Factors that increase women's vulnerabilities of becoming infected with the virus include poverty, youth, and exposure to gender-based violence. Young women are among the fastest growing populations of people living with HIV.[5]

In some countries, such as the Congo, Uganda and Zimbabwe, new research and reports cited at AIDS 2010 focus on women's vulnerability to rape, violence and HIV used as a political tool in the context of war and violent social disruption. Despite these documented vulnerabilities, women are still largely without access to any form of protection that is under their own control, instead relying on male partners for protection, further increasing their risk.

practices of criminalisation in all its forms; and the subsequent call for the decriminalisation, as well as the protection and promotion of a person's right to autonomy, dignity and non-discrimination – regardless of a person's sex, gender, sexuality, gender identity, choices and desires and/or HIV status – has been a common argument across continents and issues in most of these sessions.

However, it also became clear that although many would endorse and support the call to *decriminalise* HIV in principle, the specifics of the various interrelations, links and causalities between gender, power, sex and criminalisation are not as easily supported and endorsed across continents and sessions, as this would imply opposing and subsequently challenging the very same fundamental principles – the '*social order*' – of our perceptions and understanding of what is '*right*' and what is *'normal'.* And it is at this intersection of advocating for what is '*right*' and '*ethical*' and what is '*accepted*' in law, policy and practice that human rights are often not at the centre of the debates; that the limitation of an individual's rights often seem '*justifiable*' for the protection of the many; and that the specific realities, needs and risks of women (in all their diversities) seem to have become an '*acceptable*' status quo – one that needs to be taken into account and be recognised in policies and programmes as an '*issue apart*' in need of urgent attention.

And after a week of debates and activities on '*rights here, right now*' and '*women's rights here, right now*' the question remains of *what* we have achieved, *who* we have reached, and *whose* lives we have impacted upon. And while specific answers may differ for each and every one of us, what seems to remain is a certain reluctance to '*touch the untouchable*', to challenge the status quo, and to truly place human rights at the centre of debate, policies and actions.

An effective response to particularly women's risks, realities and needs is *now more than ever* the key to ensure that rights become realities for all people; that commitments and promises are translated into actions beneficial for everyone; and that legislative trends and the common practice of criminalisation are opposed and transformed into the decriminalisation of sex, sexuality and HIV.

Many would agree that '*there is more than enough evidence*' on the multiple interrelations between women's rights, realities and needs and women's specific risks and vulnerabilities to HIV and human rights abuses and that now is the time to move beyond '*discourse*' and '*to prioritise actions*' – for *women to say NO to criminalisation* and for all of us *to say NO to the criminalisation of women and women's sexuality*.

JOHANNA KEHLER

At the same time, government policies have often focused on women as vectors of disease, rather than *victims*, with policies that target women without accounting for their rights. In one panel devoted to the increasing criminalisation of people living with HIV, Johanna Kehler of the AIDS Legal Network (ALN) noted that new laws and court precedents that criminalise HIV transmission around the world harm women through selective enforcement, and because such laws, ironically, disproportionately impact on people living with HIV who are aware of their status. Women are more likely than men to access healthcare, including HIV treatment and testing, and are, therefore, more likely to be made legally liable for HIV transmission, despite a general female disempowerment in the realm of HIV prevention. This criminalisation of HIV transmission also applies, in some cases, to mother-to-child transmission of HIV through antenatal transmission or through breastfeeding.

…continued, serious threats to autonomy, health and security…

This combination of health policy focus on women living with HIV, when combined with a disregard for women's human rights, has led to medical abuse of women living with HIV in the context of coercive treatment policies. Women in countries as diverse as Namibia and the USA report being coerced into sterilisation when seeking medical attention for HIV while pregnant, seeking termination of pregnancy, or simply giving birth.

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THE GROWING THREATS OF CRIMINALISATION AND VIOLENCE

This criminalisation of HIV exposure or transmission looms large as a continued and increasing threat to the rights of people living with HIV, and to successful public health strategies targeting the epidemic. 63 countries have HIV-specific laws, 27 of which are on the African continent.[6] Advocacy organisation GNP+ has documented more than 600 instances of HIV transmission prosecution in more than 80 countries, with numbers growing. The United States has the largest number of cases, while African nations, such as Tanzania and Mozambique, are testing grounds for model laws that hold people living with HIV criminally responsible for HIV transmission. European countries are also experiencing an increasing number of *successful* prosecutions of HIV exposure and transmission.

In addition to the criminalisation of HIV transmission, the criminalisation of sexual and gender minorities, and sex workers, violates human rights and undermines public health efforts to adequately address the HIV epidemic in countries worldwide. Such criminalisation, particularly of LGBTQ people, is increasing across the globe. 85 countries around the world now have laws on the books '*outlawing*' homosexuality to varying degrees, ranging from bans on '*sodomy*' to '*displays*' of public affection between same-gender couples. These laws are punishable by long prison sentences and, in the case of a proposed Ugandan Bill and policy in Iran, by death.[7]

While imprisonment is itself a risk factor for HIV, such laws may have a greater negative impact by LGBTQ communities going underground and increase members' HIV risks by reducing their access to housing, employment and healthcare, increasing poverty, and undermining public health interventions.

…disregard for women's human rights, has led to medical abuse of women living with HIV…

This atmosphere of legally sanctioned marginalisation of sexual and gender minorities may also help to increase stigma and the violence associated with it. Reports of increasing incidents of '*curative*' rape of lesbians and transgendered men have continued to emerge across Southern Africa, while transgender women and gay men continue to face sexual violence and exploitation across the globe. This violence increases LGBTQ people's vulnerabilities to HIV and human rights abuses. Meanwhile, lesbian women, alongside transgender men and women, who experience much stigma remain largely marginal to the policy and research agenda in HIV and AIDS.

While the focus of the *'Vienna Declaration'*[8] is on the criminalisation of drug users and sex workers, the message from AIDS 2010 and the Global Village is clear; the scientific analysis of the importance of human rights to effective health policy embodied in the document applies more broadly to the criminalisation of people living with HIV, women living with HIV, and LGBTQ people. Just as criminalisation '*drives*' drug users '*away*' from seeking health services, it will drive away all criminalised groups. '*Stigma's*' impact on drug users' access to care and treatment along with their vulnerability to infection is similar to that of other stigmatised groups. Billions are being wasted around the world on ineffective policies that include criminalisation.

ECONOMIC CRISIS AND HEALTH IMPACTS

This wasted funding on ineffective policies is particularly problematic in a time of economic crisis. The embrace of once-controversial human rights approaches within the global HIV treatment and policy community did little to stifle the now traditional sound of chanting, protest and song at IAS 2010 in Vienna. While demonstrations highlighted a variety of significant issues relating to HIV and AIDS research, treatment, and policy, from LGBTQ rights to the rights of those co-infected with TB and HIV, the largest and most vocal protesters were those targeting donor countries, including the US, for '*broken promises*' on AIDS funding. Protesting organisations ranging from ACT-UP to the Treatment Action Campaign (TAC), called attention to decreasing funding and interest in HIV and AIDS. The Obama administration in particular, has diverted AIDS funding to initiatives that focus aid on general health infrastructure and maternal child health.

Former President '*Bill*' Clinton, a keynote speaker at AIDS 2010, and now head of his own foundation, argued that a debate about the importance of general funding versus AIDS-specific funding was one that engaged in '*false dichotomies*', since both kinds of health funding should be mutually reinforcing. Nevertheless, since July 2010, HIV and

…violates human rights and undermines public health efforts…

AIDS researchers and advocates have seen drastic cuts to the pool of available resources, which threaten to undermine the recent progress in responding to the epidemic.

…it will drive away all criminalised groups…

PEPFAR FLATLINES AS GLOBAL FUND IS GUTTED

At the conference, advocates noisily noted that the US commitment to global HIV treatment is faltering in the face of economic crisis. In May 2010, Barak Obama unveiled his Global Health Initiative (GHI), which declared a shift in emphasis from HIV funding to general health funding. Funding for the President's Emergency Plan for AIDS Relief (PEPFAR) was extended for one year, with a $3 billion boost in funding, that sector analysts noted was insufficient to increase interventions to the levels required to maintain the progress seen in recent years. 10 years of steadily increasing AIDS funding has produced a 17% decrease in transmission, a rate groups like TAC hoped would be substantially improved by well-funded support for South Africa's new policy approach.[9]

…drastic cuts to the pool of available resources, which threaten to undermine the recent progress in responding to the epidemic…

Early this month, activists' fears of a global AIDS funding shortfall were further confirmed when the Global Fund's '*replenishment*' meeting failed to raise the full $20billion needed to maintain current funding levels. At just $12 billion, funding to poor nations and NGOs that provide life sustaining treatment will inevitably fall short, with advocates predicting that the funding shortfall will reduce the number of people receiving antiretroviral drugs by 3.1 million, while an almost equal number will not receive needed TB drugs, and almost half a million pregnant women will be deprived of PMTCT services.[10]

Donors argue that these cuts in funding are attributable not only to changing health priorities, but the global economic crisis and an increasing and necessary emphasis on cuts to government services and funding worldwide. Cuts may have an impact, not only by holding back necessary improvements in treatment access, but also by reducing resources for new avenues of research, such as vaccines and/or further microbicide trials.

REFRAMING THE DEBATE ON HIV AND HUMAN RIGHTS – MAKING RIGHTS A REALITY

As they celebrate the increasing acceptance of a human rights framework for HIV policy, researchers, service providers and activists at AIDS 2010 argued that a second paradigm shift is needed to halt the epidemic and the inequalities that fuel it. Rather than *fighting* for limited resources in debates pitting maternal child health against HIV treatment, or women's' rights against the rights of LGBTQ people, activists should instead reframe the debate. In one session, entitled '*Price Check: How Much is Needed for Gender and AIDS?*' panellists suggested that people concerned with women's rights and HIV ask not '*what can we do with the little money we are given?*', but '*what do we need?*' and then '*how much will it take to get it?*'. Across the spectrum, advocates argued for a similar approach to other key

priorities; Zena Stein, one of the researchers behind the recent Tenofovir gel success similarly asks the key question '*where's the will*?'[11] for funding prenatal interventions and education on exclusive breastfeeding that is known to be extremely effective in preventing maternal-child transmission. Similar questions can be asked about the research necessary to develop and implement existing and new women-controlled prevention strategies.

True implementation of a human rights approach to HIV research, treatment and policy making will require not only a recognition of the importance of human rights and the decriminalisation of women, people living with HIV, LGBTQ persons, intravenous drug users, and sex work, but also a rethinking of the scarcity model, which pits the needs of diverse constituencies against one another.

…a second paradigm shift is needed to halt the epidemic and the inequalities that fuel it…

Vienna 2010 and the Vienna Declaration represent an important step forward in a generation-long push for a rights-based approach to HIV and AIDS, with the successes of this approach reflected in increased access to treatment and decreasing rates of transmission in some of the world's most affected countries and communities. At the same time, progress is threatened by global leaders' response to the economic crisis, which includes billions in bailouts to stabilise the financial system and fund punitive policies, along with a sense of resignation toward funding cuts for health, education and other services. In this environment, HIV and AIDS resources are seemed to be shrinking, and the dream of rejecting a scarcity model seems far-fetched.

As we move towards 2012 and Washington DC , it is important to remember that making human rights and gender inequality central elements of the HIV and AIDS agenda also seemed unlikely just ten years ago. We should recognise what activists have learned through decades of responding to HIV and AIDS: that affected communities can be their own best advocates when it comes to shifting the debate toward political will to make rights a reality. As Jennifer Gatsi, Director Namibia Women's Health Network, states '*by empowering a woman, we can see that change is coming*'.[12]

FOOTNOTES:

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3. Treatment Action Campaign. 2010. 'What are the new ART treatment guidelines'. April 2010. [www.tac.org.za/community/files/file/TreatmentLit/2010/HIVTreatmentGuidlinesBookletEnglish.pdf]
4. Susser, I. 2010. 'Finally A Microbicide Success!' In: *Mujeres Adelante,* 21 July 2010.
5. World Health Organization. 2010. *Gender Inequalities and HIV*. February 2010. [www.who.int/gender/hiv_aids/en/index.html]
6. Arnott, J. 2010. 'Where HIV is a Crime, Not Just a Virus'. In: *Mujeres Adelante.* 23 July 2010.
7. Varner, B. 2010. 'AIDS Fight Targets Laws Against Homosexuality, UN's Sidibe Says'. March 16, 2010. [www.businessweek.com/news/2010-03-16/aids-fight-targets-laws-against-homosexuality-un-s-sidibe-says.html]
8. *The Vienna Declaration*. July 2010. [www.viennadeclaration.com/the-declaration.html]
9. Boaz, P. 2010. 'Washington Debates PEPFAR Funding Ahead of Global Fund Meet'. In: *IPS News.* 2 October 2010.
10. Treatment Action Campaign. October 2010. 'Rich Donors Have Failed the Global Fund'. [www.tac.org.za/community/node/2949]
11. Stein, Z. & Susser, I. 2010. 'Will and Resources'. In: *Mujeres Adelante.* 23 July 2010.
12. Gatsi, J. 2010. 'Women are very powerful advocates...'. In: *Mujeres Adelante,* 18 July 2010.

Kate Griffiths is a writer and ethnographer based in Durban, South Africa. For more information and/or comments, please contact her at kategrif@gmail.com.

A seed of hope...
Reflection on Vienna

The Lesbian community received some recognition at this year's World AIDS Conference – although not nearly enough – which raised awareness about the fact that this is a group indeed affected by this global pandemic; just that, thus far, they have not been recognised enough as such.

Sophie Strachan

There is a great need to gather sufficient information around sexual practices of individuals with more than one gender, and to support the lesbian, bisexual and transgender communities in mobilising around the invisibility of women's sexual diversity. This invisibility will continue to deny LBT women collective and effective responses, and services, to HIV/STI and AIDS.

As an HIV positive lesbian, an acknowledgement of our needs and heightened visibility planted a seed of hope. To meet and talk with many other positive lesbians and bisexual women was not only significant, it also was very apparent that there is a large community of positive women globally needing visibility and recognition to overcome the isolation and silence that so many of us can experience.

I have spent the last four years facilitating a group for positive lesbians in London, United Kingdom. After two years, we finally managed to secure some funding for our work, which, at the time, felt like a significant achievement. However small our numbers, we had effectively raised visibility and reached women who had lived in isolation for almost 20 years, with visible mental ill-health, because they felt unable to speak to health professionals through fear of further discrimination. We reached women not only on a national level, but also internationally. We (Positively UK) are the first HIV charity in the UK to provide specialist support for this community of women.

So much more work needs to be done to give us a more truthful picture of just how much of a fundamental place the lesbian, bisexual and transgender communities have in the face of this global pandemic. And hopefully, AIDS 2012 in Washington DC will be the conference where the realities and needs of LBT women will be fully recognised and new study findings about HIV risks and vulnerabilities of lesbian, bisexual, and transgender people be at the centre of the debate.

Sophie Strachan is a case worker at Positively UK. For more information and/or comments, please contact her at sstrachan@positivelyuk.org.uk.

Doing something right...?[1]

Women in the AIDS response

Alexandra Garita

Beginning with the commitments made at the International Conference on Population and Development in Cairo in 1994, and increasingly over the past 16 years, the international community has recognised that providing a broad constellation of health services in a single location will ensure a higher quality of care and positive health outcomes. For women, that means ensuring access to comprehensive sexual and reproductive health services in one place.

Consider, for example, the circumstance of an HIV positive woman in rural Botswana. In Botswana, which has the second highest HIV prevalence rate in the world, most new infections occur in women. In order to obtain treatment, she must travel 30 kilometres by foot to a U.S.-funded clinic. The woman must travel another 50 kilometres to find a clinic that offers contraceptives that will enable her to control her own fertility, or receive screening to detect cervical cancer, a disease that disproportionately affects women living with HIV. Both clinics require separate staffing, infrastructure and overheads.

Currently, there are a number of global health initiatives that prioritise the strengthening of health systems. The US Global Health Initiative will seriously invest in women-centred approaches that can help provide for better sexual and reproductive health outcomes, and leverage significant support from other government donors and multilateral partners. The International Health Partnership is trying to build strong health systems with co-ordinated investments in disease-specific responses such as HIV, in a number of countries, primarily in Africa. Specific health-related initiatives, such as the Global Fund to Fight AIDS, Tuberculosis, and Malaria, as well as maternal health, family planning and child health initiatives, also need to examine how far they will go to expand their mandate to include broader health system issues.

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Recently, increased attention has been given to scaling up support for maternal and child health, given that the Millennium Development Goal 5 on improving maternal health,

is the least likely to be achieved by the year 2015. Although reducing maternal mortality ratios and providing universal access to reproductive health should become a greater priority, narrow and technical interventions, such as emergency obstetric care and contraceptive supplies, in themselves, will not achieve improvements in maternal, and therefore child health. Women need to be treated with care and respect, have access to an entire package of services, and have their human rights protected, in order to achieve any of the Millennium Development Goals. In addition, governments must also recommit to achieving universal access to prevention, treatment, care and support of HIV/AIDS (MDG 6), if women are to have a true chance at leading just and healthy lives. Comprehensive approaches that invest in the long-term, sustainable capacity of the health system to provide adequate care for women, and their newborns, are required.

…invest in women-centred approaches that can help provide for better sexual and reproductive health outcomes…

Civil society's meaningful participation in building stronger health systems is crucial to both better health outcomes and greater accountability on the part of policy makers. The UNAIDS *Agenda for Accelerated Country Action* for addressing women, girls, gender equality and HIV is currently being rolled out and presents an opportunity for civil society, the UN system, governments, and all relevant stakeholders to direct AIDS programming for women.

The *Agenda* contains possible actions that governments can take to ensure that women can access a package of integrated services for sexual and reproductive health, HIV, and tuberculosis. National AIDS responses must also prioritise financial and programmatic actions that uphold the rights of women and young people, and address the discrimination and stigma that often leave them vulnerable to infection. These investments must include comprehensive sexuality education for young people in

and out of schools; a strong national programme to prevent and respond to female-initiated HIV prevention methods, such as female condoms; microfinance and social protection schemes that strengthen women's economic positions and reduce their vulnerability to HIV; and programmes that engage men and boys in the fight for gender equality.

The world is at a pivotal point of defining concrete actions to transform their funding and policies into tangible changes in women's lives. Women across Asia, Africa, and Latin America know what is needed and what works. Access to sexual and reproductive health services is integral to good health for men, women, and young people, and underlies our ability to make headway in confronting other health issues as well. Foreign assistance donors and countries where they are shaping programmes to integrate and invest in sexual and reproductive health services means taking steps to end the political stigmatisation of these programmes and focus instead on the real-life health benefits.

…taking steps to end the political stigmatisation of these programmes…

All donors, including the United States and the United Nations, need to do more to increase investments in sexual and reproductive health services, including comprehensive sexuality education; support bold diplomatic programmes for the human rights of women; and engage local organisations led by women and youth.

FOOTNOTE:

1. An earlier version of this article was published in the *Mujeres Adelante* on 18 July 2010. Garita, A. 2010. 'Women's Realities: Doing something right for women in the AIDS Response?'. In: *Mujeres Adelante*, 18 July 2010, p4. [www.aln.org.za]

Alexandra Garita is the Programme Officer, International Policy, at the International Women's Health Coalition. For more information and/or comments, please contact her at agarita@iwhc.org

A rigorous gender-based analysis...[1]

On the issue of violence against women, I find it interesting to watch how the issue of violence is being taken up in the world of HIV. From the perspective of someone who has worked on the issue for many years and from a variety of angles, I see the HIV community repeating some of the steps and showing some of the tensions that also took place when GBV came onto the human rights agenda in the late 1980s and early 1990s. Then, as now, we see that it is easier to get attention paid to sexual violence.

Susana Fried

EXPANDING THE LENS OF VIOLENCE AGAINST WOMEN

Sexual violence is so palpably evocative and egregious that it generates energy and attention. The challenge is that it also runs the risk of being sensationalised in ways that mask nuance, and, sometimes, make the real individuals either invisible or as victims without agency. It has always been much more difficult in the context of human rights, and now in the context of HIV, to look at the broad scope of gender-based violence and then to understand sexual violence as a component of it.

In this context, it is important to understand that it is not only sexual violence that places women (and people, in general) at greater risk of HIV. Other forms of violence intersect with HIV – placing women and others at risk, as well as having a distinct and serious impact on women and others who are HIV positive – and targeted for violence and discrimination because of their real or perceived sero-status. One extreme form of the violence against women living with HIV is, for example, coerced sterilisation. But we don't always talk about coerced sterilisation as a form of gender-based violence. On another front, fear of violence may keep a woman from getting tested or getting treatment. Sometimes the fear or fact of violence is used to force women to share their ARVs. But these issues often get cordoned off from each other as separate, and as a result they are not always part of a larger discussion around gender-based violence and HIV (though there are certainly many women's rights, human rights and HIV organisations that take an integrated and rights-based approach). When this happens, we do a big disservice to the analysis, to the action, and to the potential partnerships that might be created by looking to the full scope of gender-based violence in the context of HIV.

Using a rigorous gender-based analysis also forces us to look at the experience of men who have sex with men and trans people, and, in particular, to understand how their vulnerability is increased by the fear or reality of violence. And as with women, the experience of being HIV positive is always inflected with the

fear and reality of violent reprisals against them, because they are gay, lesbian, or trans and HIV positive.

MOVING THE CONVERSATION FORWARD ON GBV AND HIV

The Outcome Framework for the UN Joint Programme on HIV/AIDS gives a priority to working with women and girls, with a particular focus on addressing gender-based violence – acknowledging the intersection of the two – and this will certainly present opportunities for moving the agenda forward in a cross-movement and multi-sectoral way. UNDP will also be engaging in specific work on GBV – with all women and girls, as well as with men who have sex with men and trans people – and frames these in the context of human rights, as part of the HIV Practice's broader mandate to work on human rights, gender and sexuality diversity and, more broadly, UNDP's mandate to work toward gender equality. So, for example, this includes supporting efforts to integrate GBV into national AIDS strategies and plans, to addressing violence against sex workers.

…either invisible or as victims without agency…

At the global level, the UN Secretary General's *Unite to End Violence Campaign* presents an important opportunity, especially because it has not yet fully taken up the issue of HIV with respect to gender-based violence. This is a good moment for bringing more HIV content into that campaign – especially in the context of the Millennium Declaration, the MDG Summit, and the search for programming with multi-MDG impacts. Despite the best efforts of many individuals, organisations and networks, it is still the case that in many places HIV movements, women's rights movements, sexual and reproductive health and rights movements, LGBT movements, and violence against women movements are still not talking with one another enough. The UNITE Campaign is a process that has emerged in reference to women's rights and anti-GBV movements, and it is an important place to move forward more attention to HIV in this platform.

…opportunities for moving the agenda forward…

The Vienna IAC is a valuable moment for those who work on women and HIV to continue the process of meeting together and moving discussions forward toward, for example, the MDGs. As I mentioned, there is a push to look at cross-MDG strategies…and looking at violence against women as a cross-cutting approach to addressing gender inequality, at the same time that it is linked to HIV and to women's health. Maternal health and maternal mortality,

…movements are still not talking with one another enough…

for example, in combination with HIV, is another realm where violence places women at risk of maternal ill health.

We need to continue to create spaces where we can be creative and think in new ways – Vienna is this space and the Women's Networking Zone is such a space – it is a good moment to highlight successful or new strategies and good lessons for the MDGs and for the Universal Access Review in 2011. There is a strong community present (including HIV, women's health and rights and LGBT) and it is a very important opportunity to determine how to move these conversations forward.

...we need to continue to create spaces where we can be creative and think in new ways...

RECONCILING THE EVIDENCE BASE

On the one hand, there has not been enough attention to generating a robust evidence base on women and girls in epidemiological terms – and on the other, there is a strong push from people who work on women and HIV to expand what '*counts*' as evidence.

In the human rights field, evidence is based on documentation and analysis of patterns and testimonies that echo across the world as evidence. There is a strong push to create more space for human rights style documentation and analysis as credible evidence in the context of HIV and public health.

...expand what *'counts'* as evidence...

Human rights folks say that one human rights abuse is one too many and requires action. It is not tracking numbers but patterns. If we say '*Rights here, Rights now*', how do we bring these different versions of what is the evidence that triggers a reaction into better alignment? If AIDS 2010 is a conference that has human rights as its theme, it is a good time to take up this discussion in a rigorous and clear way – for moving the AIDS response forward, for ensuring that it is a gender-transformative movement.

FOOTNOTE:

1. An earlier version of this article was published in the *Mujeres Adelante* on 20 July 2010. Fried, S. 2010. 'Special Report: A rigorous gender-based analysis'. In: *Mujeres Adelante*, 20 July 2010, pp6-7. [www.aln.org.za]

Susana Fried is a Senior Gender Adviser at UNDP. For more information and/or comments, please contact her at susana.fried@undp.org.

Ensuring safety, security and autonomy...[1]

Jayne Arnott

Gender- based violence was the focus of the oral poster session entitled '*Ensuring Safety, Security and Autonomy: Why must we overcome gender-based violence?*' on Wednesday, 21 July 2010.

Michaela Leslie-Rule introduced findings of a participatory research study that engaged a group of Tanzanian women around defining the language of love, intimacy, sexuality and violence. Leslie-Rule explored how women's responses revealed that inter-personal violence was very much a private issue and women participating in the study presented with some tolerance for inter-personal violence. When exploring what types of physical and sexual encounters were considered to be violent, the severity of the physical injury seemed to be the determining factor. Women also spoke in a manner that seemed to indicate an expectation that it was normal to experience some amount of force or coercion from partners in sexual encounters. This was not always experienced as violence.

...there is more than enough evidence...it is time to prioritise action!...

Women spoke about sexual agency and desire using proverbs and allegories that are passed down from grandmothers and women elders in the community. It is taboo for mothers and daughters to discuss issues related to sex. This type of information sharing presents opportunities for interventions that could address inter-personal violence and reduce the risk of HIV, for example, through reaching grandmothers and elders who are passing on sexual information to '*shift*' stories in ways that can better equip women to articulate female sexuality and sexual desire. Leslie-Rule noted that it is often women's lack of sexual knowledge and sexual agency that can lead to violence in sex.

Gender equality is viewed predominantly as a goal that the government must work towards, and placed in the public sphere with women articulating the need, for example, for education and economic equality and this is prioritised over gender equality in the private sphere. Women can perpetuate gender norms that support gender inequality and this limits opportunities for men and women to be co-creators of tolerant environments.

If gender equality is perceived as being something that the public sphere has to address, then the question is how can governments and public services strengthen their policies and programmes to integrate and promote gender equality both within the public and the private sphere.

The session ended on the note that there is more than enough evidence regarding the links between gender violence and HIV, the intersections, and the bi-directionality. It is time to prioritise action!

FOOTNOTE:

1. An earlier version of this article was published in the *Mujeres Adelante* on 20 July 2010. Fried, S. 2010. 'Special Report: A rigorous gender-based analysis'. In: *Mujeres Adelante*, 20 July 2010, pp6-7. [www.aln.org.za]

Jayne Arnott is the Social Policy Researcher at the AIDS Legal Network, South Africa. For more information and/or comments, please contact her at advocacy@aln.org.za.

Raising the human rights agenda...

My views on Vienna

Sonia Correra

As is well-known, International AIDS conferences are gigantic gatherings that cannot be assessed as a totality. Despite their scale and complexity, in the past, a number of International AIDS Conferences have projected a compelling image that would synthesise the policy climate and agenda for years to come. As is also well-known, the development of anti-retroviral drugs became the historical mark of Vancouver in 1996, while in Durban in 2000 the extension of access to such medications in resource-poor parts of the world began to become a global policy priority. In Toronto in 2006, the emphasis on evidence-based prevention announced the current scenario of increasing resources being invested into medical male circumcision programmes and the use of ARV as a prophylactic, while opposing views on the ABC approach to primary prevention signalled an increasing polarisation of policy responses to the HIV epidemic.

In light of this trajectory, it is not trivial that, in Vienna, *human rights* was the title and the main theme of the conference. In fact, it is somehow troubling that it has taken so long for the AIDS mainstream to fully incorporate human rights as a non-negotiable perspective in the design of the responses to the epidemic. This breakthrough, though late, was made possible because many voices situated at the margins, such as HIV positive persons, feminists, LGBT activists and intellectuals, sex workers, a cluster of social scientists and even a few biomedical researchers, have been, for many years, raising the human rights agenda in AIDS policy debates.

The colourful demonstration on July 20th that went through the Burgring before gathering at the Hofburg was the remarkable result of these ongoing and rather invisible efforts. But the *AIDS and Human Rights March* should also be placed against the backdrop of history. Firstly to recall that in 1938, Hitler paraded through the same Burgring when Austria was incorporated in the Third Reich (the Anschluss). But also to say that for those who have been part of the UN 1990 '*sex saga*' it was simply thrilling to be walking in front of the Austrian Parliament, while the crowd

was happily shouting '*sexual rights are human rights*'. Most of us who engaged in the closed-room negotiations in Cairo and Beijing could not have imagined that fifteen years later sexual rights would be spiralling in the streets.

It should also be mentioned that the AIDS and human rights agenda was present and alive in a large number of panels, workshops and satellites, including plenary sessions where Meena Seeshu spoke about sex workers' rights and Everjoyce Win about gender violence, human rights, and HIV, and Carlos Cáceres, to mention but a few key moments. Most importantly, key main obstacles to the full realisation of human rights of those affected by, or those potentially vulnerable to, HIV were also addressed, in particular criminalisation of same-sex relations, sex work, and drug use, which was the topic of a number of sessions. It is also remarkable that for the first time in history of the AIDS conferences the intersection between HIV, '*abortion*', and criminalisation was addressed in at least two formal panels (and not exclusively in the Global Village, as used to happen in the past).

A major step has therefore been made that must be applauded and appraised. However, this does not imply that the road ahead is an easy one, as the conditions of the world are not exactly favourable for the respect and promotion of human rights at large, or sexual rights in particular. It is not therefore surprising that one of the very first sessions of the Vienna Conference, sponsored by UNAIDS, was titled: *A human rights- based approach to prevention: Mission Impossible?*

...raising the human rights agenda in AIDS policy debates...

In regard to the feminist presence, agenda and visibility – in addition to the integration of '*abortion*' rights in the HIV and AIDS policy agenda, which is crucial – a series of smart and productive conversations took place at the Women's and the LGBT Networking Zones, and at a number of panels organised at the Global Village. Some interventions also happened in the exhibition area, such as the '*find the clitoris*' contest, or the *daily vulva award*, promoted by the Latina feminists, which was, by far, the most joyful experience I had in Vienna.

...troubling that it has taken so long for the AIDS mainstream to fully incorporate human rights...

Sonia Correra is with the ABIA AIDS and Sexuality Policy Watch, Brazil. For more information and/or comments, please contact her at scorrera@abiads.org.br

Why the silence...[1]

Sexual rights and HIV prevention

Jayne Arnott

Sexual rights as stand alone rights in the context of HIV prevention seem to have slipped out of the human rights discourse in relation to HIV and AIDS. For effective HIV prevention approaches we need to engage with, and talk about sexuality, support and promote sexual rights, and advocate for the right to sexual information and the right to sexual choices.

Claudia Ahumada, from the World AIDS Campaign, was one of the presenters at a satellite session on '*Sexual Rights and HIV Prevention*', on 20 July 2010. She started her presentation by noting that this was the only stand-alone session at the conference on sexual rights! We really need to challenge the '*lip service*' to integrating sexual rights into HIV and AIDS responses.

Why is it that we are not supporting women living with HIV to exercise their sexual rights? We should be outraged that positive women are being subjected to gross rights violations in relation to having sex and making (or not being able to make) reproductive choices, with violations ranging from dissuading women from having children through to forced abortion and sterilisation practices. Why the silence? If we cannot talk about sexuality, support sexual choices, and integrate these rights into HIV and AIDS responses, how can we begin to address HIV and AIDS prevention interventions, programmes and services that work and respect human rights?

Posing the question of '*What do we mean by meaningful youth participation and what hinders us from reaching this?*', Ahumada talked about what youth need in relation to sexual education and services, and argued that adults continue to make assumptions about what youth need, which often leads to barriers to access to relevant information and services, including HIV prevention services.

Ahumada further elaborated on a series of impractical laws regarding access to sexual information and services based on the age of consent that are in place across the globe and that impact greatly on youth's '*ability*' to access HIV prevention and to make informed sexual choices. In Chile, for example, if you are under 14 years old, you cannot consent to sex and if you do, it is then considered statutory rape, including sex between peers. The law further states that anyone under the age of consent, seeking information or services around sexual and reproductive health within the public health service, must be reported to the police.

So how do we reach and engage youth in information-sharing, promoting sexual rights, safer sexual activity and sexual autonomy within a climate of criminalisation, as well as measured and controlled access to sexual knowledge and services.

FOOTNOTE:

1. This is an excerpt of an article published in the *Mujeres Adelante* on 22 July 2010. Arnott, J. 2010. 'Special Report: Why the silence?'. In: *Mujeres Adelante*, 22 July 2010, pp6-7. [www.aln.org.za]

Jayne Arnott is the Social Policy Researcher at the AIDS Legal Network, South Africa. For more information and/or comments, please contact her at advocacy@aln.org.za.

Women's rights before it's too late...[1]

Women and HIV in Eastern Europe

Kate Griffiths

Eastern Europe is currently the region on the planet where rates of new HIV infections are rising dramatically, with a 66% regional increase since 2001. Ukraine and Russia are the most severely impacted, while treatment access among Eastern European countries is far below necessary, with less than a third of those who need it receiving antiretroviral therapy.

While intravenous drug use remains the primary mode of transmission in the region, some experts fear that the epidemic is on the verge of making the switch to a generalised heterosexual epidemic, which could place many more lives at risk. Sexual transmission is already the source of 42% of infections, with the sexual partners of drug users and sex workers the most at risk. As a result of this trend, increasing numbers of women are contracting HIV, in addition to being affected by their partners' status. In some countries in Eastern Europe, including Ukraine, women now make up nearly half of the population of people living with HIV.

While the pandemic in Europe may include its own unique features, as Katarzyra Palerjanik argued, women, and women with HIV *'have the same problem in every country*', disempowerment, violence, stigma and discrimination. Women also face increased biological and social risk of contracting HIV, with young women especially vulnerable worldwide.

According to Dr. Iatamaze Veruamvivi, director of the Women's Centre, the epidemic in Georgia is linked to these regional factors, as well as to regional migration, both in terms of immigration from higher prevalence countries to lower prevalence nations, but also because as these nations make their *transition* from communist systems to capitalism, increasing levels of migrant labour have helped to spread HIV. In Georgia, this has resulted in 2,300 cases of which 25% are women.

In addition to difficulty accessing treatment, basic prevention measures are also seriously lacking. Service providers report very low demand for condoms, while sexual education is limited or unavailable in most countries. According to Zhara Malyilyan of Armenia, one high school principal, when asked why sexual education is not provided, answers '*the less they know the better*'.

…service providers report very low demand for condoms, while sexual education is limited or unavailable in most countries…

Mayilyan also explains that gender norms and stereotypes make it particularly difficult for women to protect themselves from HIV. Women are generally expected to marry their first sexual partners, while unmarried men are likely to visit sex workers. Married women and sex workers are both unlikely to negotiate condom use. In one survey, women who were asked if they had ever experienced spousal or *partner rape*, most responded that they felt that providing sex on demand was

their '*duty'*. Most women living with HIV are infected through sex with male partners. These realities indicate that women are socially disempowered; in Armenia, there are no elected women leaders.

These conservative gender norms are not '*traditional*' in the sense of being timeless and ancient, instead more conservative social realities have emerged in Eastern Europe as a result of the transition, as well as the rise of fundamentalist religious trends, including Christian and Muslim organisations that oppose the de-stigmatisation of sex, condoms, sex work, drug use and people living with HIV. These movements have also helped to isolate and disempower women, as they push for subordinate roles for women and limitations on women's sexual health and reproductive rights.

A further complicating problem for people living with HIV in Eastern Europe is the deterioration of public infrastructure as part of the *transition*, including declining healthcare systems. This means that access to healthcare is limited to all citizens, while people living with HIV face stigma, including rejection from clinics where doctors and clinic staff fear that if they admit patients living with HIV, their existing clients will abandon the clinic. In some instances women with severe uterine bleeding were turned away from ambulances and hospitals, due to their HIV status.

Women living with HIV in Eastern Europe face dual discrimination, as people living with HIV and as women. This can include workplace discrimination, where women with HIV are socially isolated and often forced out of jobs. For women living with HIV whose partners die of AIDS, the situation is often particularly grim. Facing rejection by their in-laws, they are likely to loose their inheritance, their homes and often their children. The attitude is summarised in a saying which is translated as '*why would I now want a stranger in my house*'?

…promoting women's rights as a critical intervention…

Women who are also intravenous drug users or sex workers can be triply discriminated against. Women in these positions are seen by men, from police to healthcare workers to family and friends as *not having rights.* Roma women with HIV are

likewise in the situation of being triply discriminated against and are also socially isolated. They may also face increased risk of HIV and violence in that they live largely as migrants.

Finally, young women are particularly at risk, largely due to higher levels of drug use, unemployment, migration and ignorance about HIV transmission and healthy relationships. Fewer than 10% of young women demonstrate correct basic knowledge of HIV prevention information.

The Central and Eastern European Women's Network for Sexual and Reproductive Health and Rights (***ASTRA***) is promoting women's rights as a critical intervention at a key stage in the region's epidemic. This includes the right to be free of coercion and violence both inside and outside the healthcare system, and guarantees of women's sexual and reproductive rights. The organisation emphasises the importance of pre-empting forced contraception, sterilisation and abortion, practices which plague women living with HIV around the world. They also call for strong youth education in sexual and reproductive health.

…argue unapologetically for the effectiveness and justice of women's rights…

As a network of local organisations that both advocates and provides services, ASTRA is already part of the solution in a region where countries are too often divided. By bringing experts and advocates together to argue unapologetically for the effectiveness and justice of women's rights, they have already helped set the stage for effective interventions to turn the epidemic in their region around.

…promoting women's rights as a critical intervention…

FOOTNOTE:

1. An earlier version was published in the *Mujeres Adelante* on 22 July 2010. Griffiths, K. 2010. 'In Focus: Eastern Europe: Women's rights before its too late!'. In: *Mujeres Adelante*, 22 July 2010, pp1-2. [www.aln.org.za]

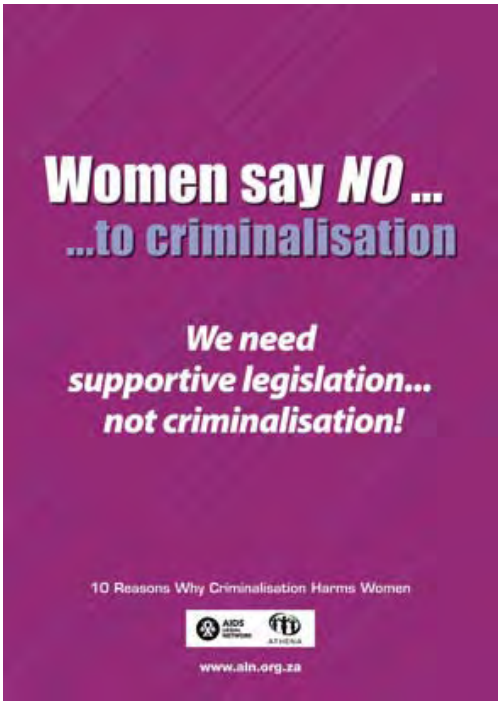
Kate Griffiths is a writer and ethnographer based in Durban, South Africa. For more information and/or comments, please contact her at kategrif@gmail.com.

Stop the spread of criminalisation and harm...

Criminalisation of HIV transmission and exposure

At the 2010 International AIDS Conference in Vienna, with the theme Rights Here, Right Now, *there was a focus on the intersections between punitive legislation, HIV transmission and public health outcomes, with a major call to specifically halt the criminalisation of intravenous drug users, and to step-up research into the public health impacts of all laws that impact on people living with HIV*

Jayne Arnott



INTRODUCTION

Women activists and rights advocates have long pointed to, and advocated against, the specific harms and violations experienced by women specifically, when punitive legislation, laws and policies interact with HIV and AIDS. This article highlights the debates at Vienna on the criminalisation of HIV transmission and exposure and the extent to which such criminalisation harms women, recognising that these specific legal developments cannot, in reality, be isolated from the plethora of other laws, policies and norms that continue to adversely impact on women's ability to realise their rights and access prevention, treatment and care in relation to HIV and AIDS.

WHERE WAS THE FOCUS IN THE CRIMINALISATION DEBATES AT VIENNA?

Moono Nyambe, of the Global Network of People Living with HIV/AIDS (GNP+), presenting at a Satellite Session on the 19th July[1], reported that the development of HIV-specific criminal laws continues to grow and expand globally. In 2005, approximately 45 countries in Europe were criminalising HIV transmission and/or exposure; by 2010, 200 countries and judicial territories globally had laws developed; and, as of July 2010, over 600 people had been prosecuted worldwide in over 50 countries. Over 25 countries in Africa have enacted HIV-specific laws within the past decade.

Nyambe did note some positive developments in that Ghana and Mauritius, amongst others, have rejected the '*Model Law*' that includes the prosecution of transmission, and the reversal of Sierra Leone's policy of allowing prosecutions of vertical transmission of HIV.

At the same session[2], Johanna Kehler of the AIDS Legal Network (ALN) presented arguments as to how the criminalisation of HIV transmission and exposure '*harms*' women, including how such laws increase internal and external stigma, discourage HIV testing and treatment, increase the risk of gender-based violence and abuse, and limit women's sexual and

reproductive rights.[3] Laws that '*intend*' to protect, actually punish those most likely to be aware of their HIV status, who are predominantly women, particularly in countries where the epidemic is primarily heterosexually transmitted. It was recognised that advocating against criminalisation of HIV transmission and exposure was complicated by the support of some women's groups for these very laws, which are perceived to '*protect*' women.

...developing insights and advocacy strategies for change in the global south... seemed lacking...

The only session of the conference[4] that focussed exclusively on the criminalisation of HIV exposure and transmission, confirmed an emerging trend of increasing incidences of individual prosecutions, particularly in the global north, which rightfully calls for, amongst others, increased litigation tactics. However, developing insights and advocacy strategies for change in the global south, with feminised and generalised epidemics, and where persecuting HIV transmission and/or exposure interacts and is enmeshed with a plethora of laws criminalising, amongst others, termination of pregnancy, homosexuality and sex work, seemed lacking.

The growth of HIV criminal laws in Africa, for example, may not be used to prosecute individuals in numbers, but they are '*policing*' communities, increasing stigma, supporting rights violations and creating barriers to accessing services. Most of these laws are so broad as to criminalise vertical transmission of HIV, make disclosure mandatory, promote mandatory HIV testing, and are impacting primarily adversely on women.

In a presentation titled '*Women and the criminalisation of HIV transmission: Law reform setbacks and successes*'[5], Johanna Kehler highlighted examples from Southern Africa where, for instance, the law in Malawi calls for pre-marital HIV testing, Tanzania's HIV-specific law calls for immediate disclosure of HIV status, and in Mali there is a legal duty to disclose within six weeks of diagnosis. These clauses impact significantly on women who are predominantly being tested for HIV at antenatal facilities and can face violence, abuse and abandonment when disclosing their positive HIV status.

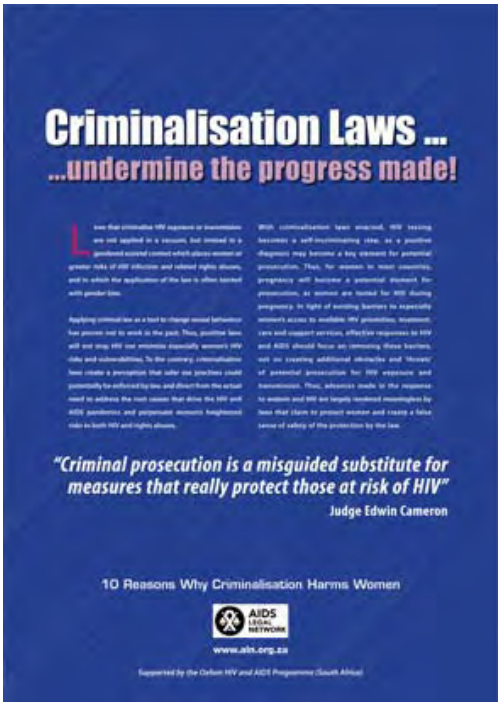
In a session titled '*Leaders against criminalisation of sex work, sodomy, drug use or possession, and HIV transmission*'[6], Michel Sidibé, Executive Director of UNAIDS, spoke to the criminalisation of HIV as not only oppressing '*vulnerable*' groups, but singled out women in particular as the group with no access to justice. There was a recognition that strategic advocacy shifts are needed and that we could not continue, in an ad-hoc way, to prevent people going to jail.

...strategic advocacy shifts are needed...

WHERE WERE THE WOMEN IN CRIMINALISATION DEBATES AT VIENNA?

There was recognition that women were particularly at risk of being affected by criminal HIV laws, but there were also calls for more evidence to be gathered to support this in order to impact on advocacy efforts. It was noted by Susan Timberlake,

from UNAIDS, in a satellite session[7], that the evidence for the negative impact of criminalisation is largely anecdotal, and this is often insufficient to convince public health officials or legislators.



Advocacy strategies to address the specific harms to women were presented at the same session, and included building alliances across human rights, women's and AIDS organisations to oppose criminalisation laws, and awareness raising, particularly among women's organisations, about the adverse impact of criminalisation laws on women. Furthermore it is crucial to raise awareness and enhance capacity among women, particularly positive women, on criminalisation clauses and laws, and their implications.[8]

It is critical to engage in law reform processes at the time of drafting legislation that proposes the criminalisation of HIV exposure or transmission, as well as lobby policy makers, to remove criminalisation clauses from existing legislation.

...often insufficient to convince public health officials or legislators...

With regards to individual cases, advocates need to engage with the judiciary to facilitate less gender bias in the application of the law and to monitor the application of criminalisation laws, especially where women are charged, towards building an '*evidence base*'.

It was further recommended that National AIDS Councils need to be engaged to revisit their national plans, and prioritise '*root causes*' of women's HIV risks and that we need to oppose all forms of criminalisation.

Other advocacy strategies put forward were largely un-gendered and included building a credible and scientific base of evidence regarding HIV transmission and exposure, to use as defence in individual prosecutions and not just addressing governments, but engaging parliamentarians in public dialogue, creating spaces for social dialogue, ensuring access to justice, and investing in capacity building in order for people to claim their rights and increase their advocacy from the ground.

It was agreed that there was a critical need to develop a population-level evidence base that could confirm the negative public health consequences of criminalisation. This must come from analysis of the observations, and experiences of advocates and people living with HIV at grassroots level, across countries. It was recognised that more needs to be done to improve people living with HIV's knowledge of laws and their rights, as well as their access to legal support and services. This needs to take place in a context of broader efforts to reduce stigma and discrimination.

CONCLUDING REMARKS

The central debate and challenge that face women's rights activists, advocates and organisations when attempting to bring to the fore the specific realities and risks women face in relation to HIV and AIDS, is how to promote law and policy change and address rights violations when women's realities and risks are not being fundamentally recognised, and the context that women find themselves in, not their '*characteristics*', fail to be addressed in a manner that can influence real and lasting change.

The impact of the criminalisation of HIV transmission and exposure on women cannot be analysed in a vacuum. Women are '*criminalised*' and '*prosecuted*' for HIV within society, even in the absence of criminal laws. Women are mostly blamed for being HIV positive, blamed for transmitting the virus to their infants, and blamed for bringing HIV to the family, and are often labelled, stigmatised and ostracised.

Within this context, at the same time, there is an increasing movement to place public health imperatives before human rights, with HIV testing campaigns increasingly losing their rights-based focus and resulting in '*forced*' HIV testing practices. In April 2010 a major HIV testing campaign was initiated in South Africa, encouraging everyone to '*take responsibility and know their status*'. Women are being caught-up in this campaign when accessing antenatal care, and increasingly '*forced*' to test for HIV. The focus on HIV testing to prevent vertical transmission means that women's sexual and reproductive rights, especially of positive women, are being further limited, violated and/or denied. The support for, and growth in criminal HIV laws adds another level of risk and rights violations to women and reinforces gender stereotypes and gender-based violence. It also impacts more severely on certain populations of women already stigmatised and often vilified, such as sex workers.

...facilitate less gender bias in the application of the law...

The development of a criminal law to police individual sexual behaviour and punish HIV transmission and/or exposure already impacts more severely on women, given unequal gender relations and male dominance in sexual relations. Women are already disadvantaged regarding negotiating safer sex and avoiding sexual violence. Add the real difficulties and dilemmas women face regarding disclosure to their sexual partners and

…the very presence of these laws can deter women from accessing health services and place additional barriers to HIV testing and disclosure…

the context is one that places women more vulnerable to being infected with HIV and to transmitting HIV. The very presence of these laws can deter women from accessing health services and place additional barriers to HIV testing and disclosure.

Criminalising HIV transmission and exposure allows for the institutionalisation of blame and shapes popular thinking on the issue. This can result in the re-enforcement of, and increase in gender-based violence and sexual and reproductive rights violations of women.

It is time to take the '*10 Reasons Why Criminalisation of HIV Exposure or Transmission* Harms *Women'* forward, to mobilise and further develop and deepen our advocacy work, and stop the spread of criminalisation and harm to women.

FOOTNOTES:

1. Nyambe, M. 2010. 'Global overview of criminal laws and prosecutions for HIV exposure and transmission'. Paper presented at the XVIII International AIDS Conference, 18-23 July 2010, Vienna, Austria.
2. Kehler, J. 2010. 'Criminalisation Harms Women: Reasons & Advocacy Responses'. Paper presented at the XVIII International AIDS Conference, 18-23 July 2010, Vienna, Austria.
3. 10 Reasons why Criminalisation of HIV Exposure or Transmission Harms Women. [www.aln.org.za]
4. Where HIV is a Crime, Not Just a Virus. Session on 22 July 2010 at the XVIII International AIDS Conference, 18-23 July 2010, Vienna, Austria.
5. *Law Reform in the Context of HIV: Are Human Rights Protected or Compromised?* Session on 19 July 2010 at the XVIII International AIDS Conference, 18-23 July 2010, Vienna, Austria.
6. Session on 22 July 2010 at the XVIII International AIDS Conference, 18-23 July 2010, Vienna, Austria.
7. *Criminalisation of HIV Exposure and Transmission: Global Extent, Impact and the Way Forward*. Session on 19 July, 2010 at the XVIII AIDS Conference, 18-23 July 2010, Vienna, Austria.
8. Kehler, J. 2010. 'Criminalisation Harms Women: Reasons & Advocacy Responses'. Paper presented at the XVIII AIDS Conference, 18-23 July 2010, Vienna, Austria.

Jayne Arnott is the Social Policy Researcher at the AIDS Legal Network (ALN). For more information and/or comments, please contact her at advocacy@aln.org.za.

Conflicting messages...

The Pope, Catholicism and HIV

The Roman Catholic Church has been suffering a decline in membership and clergy in most areas of the world, except on the African continent, where the church continues to maintain a strong hold. Nigeria is now home to one of the world's largest catholic seminary, with other African nations following suit very closely behind. The sexual abuse scandals that were plaguing the Catholic Church in Europe earlier this year seem to, however, have had limited impact on the Catholic Church and its followers in Africa.

Sophie Strachan

A recent visit from Pope Benedict XVI to the UK led to two leading charities, Family Planning Association and National AIDS Trust[5], to issue a press release highlighting the discriminatory nature of the Pope's statements and dismissive approach toward modern day teachings on sexuality, and sexual health and well-being, illustrated by statements such as the teaching of modern contraception '*is intrinsically evil*'.

The Catholic Church's well-known position on '*abortion*' further places women's health and lives in danger. Evidence, historically and globally, shows that preventing women from accessing safe and legal abortion does not stop abortions; instead it forces women to take drastic actions, seeking illegal and life-threatening abortion procedures, sometimes with no general anaesthetic. The Pope's teachings on abortion only serve to perpetuate this situation.

Violence against women and girls is a leading factor in the *feminisation* of the global AIDS pandemic. The impact of both HIV and violence against women are exacerbated by non rights-based approaches, a failure to protect sexual and reproductive rights, and laws that are discriminatory against women generally, and women living with HIV and AIDS in particular. Denying women their human rights through a person's religious teaching, may be a very powerful tool to influence people's perceptions, but remains a clear abuse of power.

The abhorrent discrimination expressed by the Pope in 2008 toward the public '*needing to be protected from homosexuality*', is yet another example of this. The damning impact this inflicts upon the tireless work of the NGOs trying to overcome the high levels of stigma that perpetuates the wheel of persecution toward sexuality and gender identities and on people who do not conform to social standards of femininity and masculinity is unprecedented, as this forces people not to disclose, to live a secret, to compromise their truth, to deny themselves their sexual and reproductive rights, and practice behaviours that leave them at greater risk of exposure to HIV and to sexually transmitted infections. Statements like these also manifest the perpetuation of abuse

...may be a very powerful tool to influence people's perceptions, but remains a clear abuse of power...

of individuals' rights to self-expression through their sexuality regardless of gender and sexual orientation, and the freedom and right to sexual pleasure within any relationship be that heterosexual, men who have sex with men (MSM), and/or women who have sex with women (WSW).

In 2009, the official Roman Catholic Church policy towards controlling the AIDS pandemic did not allow the use of condoms, with the Pope proclaiming that '*the use of condoms increased the spread of HIV*'.

This statement caused great controversy amongst leading bodies addressing the spread of HIV, and had a potentially damning effect on prevention methods with proven evidence of successes. The World Health Organisation (WHO) responded at the time by saying that consistent and correct condom use reduces the risk of HIV infection by 90%, and that:

> *Incorrect statements about HIV and the use of condoms are dangerous when facing a global pandemic which currently affects 42 million people worldwide.*

Such ignorance on condom use, as portrayed by the Catholic Church, creates more fear and grave concern, especially as it comes from a figure who wields significant influence and power. The Vatican's encouragement on sexual abstinence to prevent the spread of this '*disease*', once again, does nothing other than to further the discrimination against people living with HIV, and denial of a person's fundamental sexual and reproductive rights, as well as stigmatisation and persecution of expressed sexualities and gender identities.

The Pope's power as an individual is unparalleled; there are currently 1.16 billion members of the Roman Catholic Church worldwide. With such influence, and a growing '*membership*' to his church, how damning are his ignorant messages when it comes to addressing the global HIV and AIDS pandemics, and recognising people's sexual and reproductive rights!

…forces people not to disclose, to live a secret, to compromise their truth, to deny themselves their sexual and reproductive rights…

The question remains of how do '*we*' address and respond to such conflicting messages, greatly impacting on people's rights and risks within the global pandemics? The answer seems to lie in adopting a 'rights-based approach', but will the church be willing to '*hear*' this?

FOOTNOTE:

1. For further information please go to www.fpa.org.uk (Family Planning Association) and/or www.nat.org.uk (National AIDS Trust).

Sophie Strachan is a case worker at Positively UK. For more information and/or comments, please contact her at sstrachan@positivelyuk.org.uk.

The need to move beyond...[1]

We know that despite increasing evidence of the need for HIV and health-related interventions for same-sex practicing people, there are limited formal HIV prevention, testing, treatment, care and support programmes targeting men who have sex with men, and even fewer for women who have sex with women.

Mmapaseka 'Steve' Letsike

We know that despite increasing evidence of the need for HIV and health-related interventions for same-sex practicing people, there are limited *formal* HIV prevention, testing, treatment, care and support programmes targeting men who have sex with men, and even fewer for women who have sex with women. Interventions remain scarce for many critical populations in many countries, and same-sex practicing Africans are one of them. Without immediate attention to this human rights and public health crisis, efforts to effectively respond to the AIDS pandemic in Africa may be seriously undermined and potentially reverse any gains made in the response to HIV and AIDS.

...social vulnerability to HIV is not an innate condition, but the result of legal, political and economic inequalities...

Persistent violations of human rights are exposing same-sex practicing people to increased risk to HIV and circumscribing their ability to protect themselves, their families and their partners. The denial of basic human rights as a result of sexual orientation may well be the most significant social risk factor for same-sex practicing Africans. Social vulnerability to HIV is not an innate condition, but the result of legal, political and economic inequalities that lead to an inability of people to protect themselves from exposure to HIV, or to control its impact on their lives.

There is a continuous need to draw attention to the lack of specific HIV programming and services; as well as the actions and inactions of governments, healthcare providers, and foreign donor contributions to HIV vulnerabilities, when same-sex practicing people face discrimination and unequal treatment in obtaining healthcare, safer-sex supplies, information or treatment.

We need to move beyond these notable exceptions and begin to respond right here and right now!

FOOTNOTE:

1. This is an excerpt from an article published in the *Mujeres Adelante* on 19 July 2010. Letsike, M.S., 2010. 'News from the margins: The need to move beyond'. In: *Mujeres Adelante*, 19 July 2010, p3. [www.aln.org.za]

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

Invisible sexualities...[1]

Locating lesbians in the response to HIV

Kate Griffiths

Despite the obvious fact that HIV is often a sexually transmitted virus, stigma continues to render invisible the sexualities of those most marginalised by gender bias and heteronormativity. According to activists who gathered in the Human Rights Networking Zone on Tuesday, 20 July 2010, to discuss this marginalisation, the result of this stigma is that very little is in fact known about the HIV transmission and living positively with HIV among lesbians and women who have sex with women (WSW). None of the sessions in the main portion of this conference address the specific prevention or treatment needs of WSW.

Panellists lamented the common assumption that lesbians are not affected by, or at risk of contracting HIV, noting *'changes in identity and sexual practices'* among lesbian women, including the use of sex toys and lesbian-identified or bisexual women who have sex with women and with men. In part because there is little research on the subject, only one case of sexual transmission between women has been documented. Nevertheless, this does not mean that lesbians are free of HIV risk stemming from diverse sexual practices, drug use, as well as gender-based and homophobic violence and rape.

Susana Fried, of the UNDP, pinned the problem of invisibility not only on homophobia, which renders lesbians

...stigma continues to render invisible the sexualities of those most marginalised by gender bias and heteronormativity...

invisible in the world of HIV policy and programming more generally, but also on an approach to sexuality in the public health field that divides '*sexual health*' and '*sexuality*' from '*reproductive rights*'. She argued that this unnecessary division stems from a sexist blindness to the importance of women's sexual pleasure and sexual choices.

> *Instead of focusing on women's sexual choices, we are too focused on women's right to refuse sex.*

A related theme was the importance of focusing on *'sexual practices',* in addition to sexual identities, when educating women about the risks of HIV. By doing so, health information education – and potentially research – can be inclusive not only of lesbians, and bisexual women, but also of trans women and trans men of various sexual orientations, and go beyond hetero-normative definitions of sex, which may even cloud epidemiological and scientific studies of sexual practices between women and men.

In addition to a lack of effective research and information on the risks and practices of WSW, lesbian women living with HIV also face specific problems. Isolation and lack of support are significant threats to mental and physical health, as is the stigma that many lesbian and bisexual women face in healthcare contexts. Lesbian and bisexual women living with HIV also face increased risk from sexual violence and drug use.

…this does not mean that lesbians are free of HIV risk stemming from diverse sexual practices, drug use, as well as gender-based and homophobic violence and rape…

This problem of invisibility and isolation is particularly ironic, as lesbian women have played a strong role in supporting the rights of gay men throughout the history of HIV and AIDS advocacy. According to one commenter from Argentina, political mapping there has also demonstrated the critical connecting role that lesbian women play between feminist organisations and LGBTQ groups, a core alliance in the movement for human and health rights.

…this unnecessary division stems from a sexist blindness to the importance of women's sexual pleasure and sexual choices…

As it turns out, lesbians may seem to be *invisible* at Vienna 2010, but for those that look more closely, WSW can be found at the centre of the global response to the pandemic.

FOOTNOTE:

1. This is an excerpt from an article published in the *Mujeres Adelante* on 19 July 2010. Letsike, M.S., 2010. 'News from the margins: The need to move beyond'. In: *Mujeres Adelante*, 19 July 2010, p3. [www.aln.org.za]

Kate Griffiths is a writer and ethnographer based in Durban, South Africa. For more information and/or comments, please contact her at kategrif@gmail.com.

Relegated to the Global Village...[1]

Trans women and the AIDS response

Kate Griffiths

The trans women's network from Latin America and the Caribbean hosted a session that highlighted the lack of attention paid to the specific issues affecting trans women in the fields of HIV advocacy and research.

While the speakers, Marcela Romero and J. Villazan, opened by discussing the issues affecting trans women in Latin America and the Caribbean, the session quickly evolved into a workshop on the needs of trans women from every country.

Villazan highlighted the lack of research on trans women and HIV in her region, where only two studies specifically track prevalence among this population, suggesting that Peru and Argentina have rates as high as 35% among trans women. According to JoAnne Keatly, speaking form the floor, rates are similar among San Francisco's trans population with rates among African American trans women as high as 56%.

Nevertheless, researchers continue to neglect trans women, a population who is vulnerable to HIV co-factors, including violence and drug use, but who are also likely to survive as sex workers, and who in some countries may play a central epidemiological role. Instead, government agencies, including the Center for Disease Control in the United States, include trans women in the research category '*men who have sex with men or MSM*'.

This elision goes beyond a failure of the research agenda, to the funding structures of advocacy and service delivery, as well as to the representation of trans women at the main session of the IAS conference this week. Said Keatly:

> *…I am angry. I am angry at the organisers of this conference, because I feel we must be heard. Instead we've been relegated to the Global Village and offered a stage to do drag shows...*

By failing to distinguish between populations of people living with HIV who are gay men and those who are trans women, the statistics ignore what may be an even greater crisis among trans women, and conceal the possibility of diverse transmission modes and mechanisms. Trans women activists argue that funding MSM led organisations for trans programming also leads to a lack of trans representation at the organisational level, and to continuing increased marginalisation.

These concerns of invisibility and marginalisation echo those of lesbian and bisexual women who are also battling stigma and marginalisation in the movement for health and human rights.

FOOTNOTE:

1. An earlier version was published in the *Mujeres Adelante* on 22 July 2010. Griffiths, K. 2010. 'News from the 'margins': Relegated to the Global Village'. In: *Mujeres Adelante*, 22 July 2010, p3.[www.aln.org.za]

Kate Griffiths is a writer and ethnographer based in Durban, South Africa. For more information and/or comments, please contact her at kategrif@gmail.com.

Included in prevention debates

Microbicides and solutions for positive women

Ebony Johnson

Women worldwide are celebrating a win for HIV prevention, women's rights and scientific discovery. The trial results are in and have shown that Tenofovir gel microbicide has a 39% reduction in HIV transmission, and a reduction in half of herpes simplex virus (HSV2). Those results are amazing and will pave the way for greater investments and larger trials.

However, as the possibility of women having a microbicide draws closer, the messaging must move with it. Good science must be accompanied by great advocacy and clear messaging. While women will hear that a microbicide will some day in the near future offer some protection against HIV and herpes in women who are HIV negative, women must also be informed that a microbicide is only partially effective against HIV and HSV2. The messaging must be clear, simple on both the strengths and limitations of microbicides. Women must be informed that a microbicide is a new tool in the prevention toolbox, and there are still risks for other STIs and unplanned pregnancy. Clear messaging must still inform women that with impending availability of a microbicide, condoms are still key, and should not be abandoned. Rather, it is important that women know that condoms should remain in play and be complemented by microbicides.

...good science must be accompanied by great advocacy and clear messaging...

...messaging must be clear, simple on both the strengths and limitations of microbicides...

Despite the overwhelming joy of the trial results, it is a sobering moment for women living with HIV. Microbicides that are projected to save countless women worldwide from being infected with HIV offer no new solutions for women living with HIV who are still without the desperately needed tools to prevent re-infection, STIs and unplanned pregnancies. The Tenofovir gel, when available, will be expressly for use by women who are HIV negative. As such, women living with HIV must remain vigilant and passionate to advocate for equally promising women-delivered prevention tools that are safe and effective for use by HIV positive women. This means that positive women must ensure that their rights to healthy, satisfying and safe sexual lives are respected and met with research that supports those rights.

While the rally cries, women living with HIV will continue to push for microbicides and other new prevention technologies; positive women who face immense vulnerabilities around sex and choice must be committed to their efforts of being included in prevention debates.

Ebony Johnson is with the International Community of Women Living with HIV/AIDS (ICW). For more information and/or comments, please contact her on femme_poz@yahoo.com

Prevention justice for women...[1]

Naina Khanna, Waheedah Shabazz-El

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

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

Achieving prevention justice for women will also require research and investment to promote a structural and collaborative response to the HIV epidemic that truly upholds women's human rights, including locating comprehensive sexual and reproductive health services within HIV services. It will necessitate increased investment in HIV prevention overall, and implementing a more comprehensive and sophisticated system to target and resource services for communities at structurally elevated risk for HIV – not just individuals who self-report behavioural risk. It will mandate increasing diversity, usability, accessibility and affordability of HIV prevention mechanisms that can be controlled by women. […]

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

FOOTNOTE:

1. Excerpts from an article published in the *Mujeres Adelante* on 19 July 2010. Khanna, N. & Shabazz-El, W. 2010. 'Special Report: HIV Prevention Justice: Not optional for women'. In: *Mujeres Adelante*, 19 July 2010, pp6-7. The full article is available on www.aln.org.za.

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

Microbicide Success: New opportunities for women

Zena Stein and Ida Susser[1]

The success of the first microbicide ever shown convincingly to prevent HIV in women was announced in Vienna at the International AIDS Conference, in July 2010. A vaginal gel, applied by a woman at any time in the 12 hours before sexual intercourse and then again at any time within 12 hours after intercourse, was found to significantly reduce the risk of HIV infection in women.

On the basis of the argument outlined below, we propose that this gel (1% Tenofovir) is both safe enough and effective enough to be made immediately available, under controlled conditions, to women in high risk populations. The gel, if widely distributed, could be expected to reduce the number of HIV infections without harm to those who choose to use it. It has been estimated that in the next five years the wide use of this gel could avert thousands of new infections in South Africa alone.[2]

One must bear in mind that every woman who does become infected with HIV will, in time, require treatment for the rest of her life. Prevention is not only humane; it is also sensible health policy.

…prevention is not only humane; it is also sensible health policy…

THE RESULTS AND MOVING FORWARD

The effectiveness of the Tenofovir gel was tested among 889 women in KwaZulu Natal and published in Science.[3] Over 30 months, the incidence of new HIV infections was compared among women using a 1% vaginal gel containing Tenofovir, against those using a placebo gel with similar appearance, taste and consistency. Among those using the Tenofovir gel, the overall result was 39% protection (with the rate of HIV infection reduced from 9.1% among those not using the gel to 5.6% among women using the gel) – certainly statistically significant. Among the 336 participants who used the gel consistently 80% of the time, protection was 54% (with the rate of HIV infection reduced from 9.3% to 4.2%); also clearly significant.

Given this result, we may ask, where do we go next? As one senior researcher wrote us before attending the 85 member conference held on this topic in Johannesburg in August 2010:

> *As you know, for drug regulators the standard for licensing is TWO independent studies with P less than .05, and we have landed in the dreaded no-man's land where a new placebo-controlled trial will be difficult to implement – politically, practically and ethically.*

Indeed this high level conference, attended by WHO, UNAIDS, USAID, South African governmental bodies, funders, researchers and other stakeholders surprisingly recommended further randomised control trials (using placebos), one ongoing and one to be newly launched in South Africa. These further trials involve the ethical dilemma of assigning thousands of women to a known inferior treatment, raising various ethical challenges. Such further trials will almost certainly delay the roll-out of a source of protection for women for a further three or more years.

The first question for women across the world, especially for those at high risk of HIV infection, and for the men who join with us in our concern, then becomes '*What is the standard that drug regulators should require?*'

A close reading of the current USA Food and Drug Administration (FDA) Code of Federal Regulations reveals that the approval of new drugs does not demand two randomised controlled trials. In fact, it carefully specifies the criteria required before a planned study can be judged as adequately designed and well-controlled.

The current trial included large numbers of women involved, careful monitoring of all the women's behaviour in diverse ways, significant risk reduction, and a key finding of a dose response relationship between use of the gel and prevention. Some people have called the CAPRISA trial only a test of concept or a preliminary study.[4] However, in fact, the KwaZulu Natal trial satisfies requirements to be judged as an adequately designed and well-controlled trial. Hence, there is every reason for the FDA, and other regulatory bodies, to release this gel for general use. Nonetheless, prudence calls for the distribution of the gel to be monitored and only provided to women under certain conditions with prior testing for eligibility.

…the ethical dilemma of assigning thousands of women to a known inferior treatment…

POSSIBILITY OF HARM

For every new drug, including Tenofovir, there is always a possibility of harm. However, Tenofovir is an antiretroviral drug that has been safely used as a pill by many thousands, if not millions, of HIV infected women and men all over the world. Thus, the likely side effects for taking the drug by mouth are few and well-known. However, far fewer women have used Tenofovir as a vaginal gel. Among the over 400 participants in the CAPRISA trial who did use Tenofovir gel, adverse events were few and carefully studied. No Tenofovir-related resistant mutations have been detected among the 35 women tested of the 38 who acquired HIV infection while using the gel. The study showed no adverse effect of use of the gel on pregnancy outcomes although, again, numbers were few.

It is always possible that after thousands more women have used the gel in a roll-out (which should be monitored), some adverse effect might appear, for instance, in relation to renal dysfunction, or hepatitis, or as mentioned above, pregnancy. These and other adverse events are unlikely to occur in sufficient numbers in a repeat randomised controlled trial, as again too few women will be included for such rare occurrences to be discerned. So, drug regulators and public health advocates should certainly emphasise post-marketing studies for further possible findings about the potential harm from using Tenofovir gel.

BENEFITS

Will the gel be beneficial, less so or more so, in other populations? It is always possible that among a different set of women in different circumstances the protection may be less than half, even among high users, as it was here. However, it is extremely unlikely that there would be no protection at all, because the confidence intervals in the KwaZulu Natal study show that 95% of the women who used the gel most of the time did benefit from its use. The confidence intervals have been mentioned by some as lowering actual '*confidence*' in the result. In practice, they strengthen inference, because they show that among high adherers in the use of the gel, 95% of women benefited from the gel so that their HIV infection rate lay between 2.1% and 7.6%, whereas for 95% of high adherers among placebo users, the infection rate lay between 6.0% and 13.7%; hardly overlapping.

We note also that the infection rate of another widespread infection, HSV 2, was halved with the use of Tenofovir. This was unexpected, but very important, because HSV 2 is widespread, and seems, in those infected, to enhance the risk of contracting HIV.

…we cannot agree that equipoise can be achieved in current and future randomised controlled trials in which a placebo vaginal gel is to be administered…

ROLL-OUT VERSUS MORE RANDOMISED TRIALS

It was quite clear from the test results that the more closely the participants followed instructions for use, the greater the protection achieved. Once the gel has been released, much work should follow in terms of enhancing its effectiveness: operational research, post-marketing monitoring, and Randomised Encouragement Trials. These studies need to be carefully designed and widely implemented, especially among women at high risk, whether in Africa, Haiti, the US or elsewhere.

ADVANTAGES OVER RANDOMISED CONTROLLED TRIALS

Observations based on these studies will have several advantages over randomised controlled trials. The first is that they do not challenge the *equipoise rule*, eliminating the serious ethical infringement of assigning some women, without their knowledge, to a probably inferior treatment.

Here we need to consider *equipoise* in more detail. *Equipoise* is a term used by ethicists to describe or justify the blind and hence non-manipulative assignment of participants to different treatments. The subjects under study are told at the start of the trial that the experimenters do not know which treatment may

help and which may not. Clearly, *equipoise* cannot be achieved in case control trials from this moment, if some women will be given a Tenofovir gel, while others will be given a placebo gel. A very serious issue is raised thereby, both for ongoing trials and for future trials, so as not to raise the question of unethical standards neither among South African women, nor for those in the other countries in which these trials are to be conducted.

…an honest contract could be achieved with trialists…

We have been told by participants that this question was discussed at the recent Johannesburg meeting, but not on what grounds it was resolved.

Following on what we have discussed above, and on many discussions we have pursued with others, both in person and in correspondence, we cannot agree that *equipoise* can be achieved in current and future randomised controlled trials in which a placebo vaginal gel is to be administered.

…we cannot risk false steps now, when an effective harm reduction procedure is almost within our grasp…

One possible way around this problem resides in the way in which the consent to participate is framed: for instance, if we invite women to participate in a trial in which they are informed, at the start, that one of the gels to which they will be (unknowingly) assigned to is not expected to reduce their risk of HIV infection, while the other is likely (or, has already been shown) to do so. Nevertheless, the consent form will have to continue that the current trial will contribute more understanding about how much their risk could be reduced. With this kind of '*informed*' consent, the number of participants may be slightly less than expected, but to compensate for that, an honest contract could be achieved with trialists.

Institutional Review Boards have been tasked with ensuring *equipoise*, and both Community Advisory Boards and Data Safety and Monitoring Boards are, to some extent, also responsible for representing the interests of women recruited to trials. In Africa, trials have been particularly active in explaining the purposes and theories of randomised controlled trials. After decades of advocating for human rights for women, we cannot risk false steps now, when an effective harm reduction procedure is almost within our grasp. This is the first reason why we suggest that rather than continuing randomised control trials, research should proceed with a closely monitored roll-out of the gel. In future trials, comparisons can be made between different strengths of the gel, different encouragement strategies, or other differential procedures, but without the need for a placebo arm of the study.

The second advantage of post-marketing strategies is that they will be carried out in real life situations, so that the experience of all women who opt to use the gel and those who serve them, informed by current understanding of its benefits and possible hazards, will add directly to knowledge and experience in the use of the gel. The third advantage of these approaches is that the gel will reach more people more quickly.

WHERE TO GO FROM HERE?

Of course, this is where we need input from women and health services from a range of different localities and situations. Early field experiences will pave the way for the roll-out of improved preparations, applicators and procedures, as they become understood and available.

The use of this gel will not be dependent on the profits that will accrue to pharmaceutical firms, since it is licensed to the South African government – it can be made available to people in low resource countries at very low cost. This makes it all the more critical that what has been accomplished and the research that is planned for better understanding and improving the gel, must be transparent, and the scientific clinical, biological, epidemiological and statistical issues be explained and studied by all who care about harm reduction and prevention.

…it can be made available to people in low resource countries at very low cost…

The MCC and the FDA should be seen as collaborators who can be convinced of the importance of the release of the gel to the public, rather than an inflexible wall. We must devise, together with them, an open trial that enables women, as fully as we can, and educates them about the pros and cons of the use of the Tenofovir gel. We have already been coping with the behavioural issues involving partial protection from the risk of HIV infection. For men, following medical male circumcision, this presents one kind of a problem. For women, no microbicide likely to be available for years is expected to be more than partial, and yet, we see their value…whether 40% or 50% or 60% effective. So, an open trial would be meaningful and the report of use/non-use would convey to trialists the anticipated reduction in HIV infection rate.

We very positively appreciate and understand the key role of research in prevention of HIV. But we urge that the need for research should not delay the use of what we currently have, and that research truly moves us onwards from where we are now.

FOOTNOTES:

1. We want to thank Anke Erhardt, Director of the Columbia University HIV Center, for convening a faculty seminar on this paper and the participants for their constructive commentary.
2. William, B.G., Abdool Karim, S.S., Gouws, E. & Abdool Karim, Q. 2010. 'The impact of Tenofovir gel on the epidemic of HIV in South Africa'. Paper presented at the XVIII International AIDS Conference, Vienna, 18-23 July, 2010.
3. Abdool Karim, Q. et al. 2010. 'Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women'. In: *Science,* 2010:329, pp1168-1174.
4. For information on the CAPRISA trial and arguments, see FHI and the Centre for the AIDS Programme of Research in South Africa. 2010. CAPRISA 004 Trial: Summary Sheet of Facts. Research Triangle Park, NC USA, July 2010. [www.caprisa.org/joomla/Micro/CAPRISA%20004%20Summary%20factsheet_20%20July%202010.pdf]

Zena Stein is an epidemiologist and Professor (Emerita) of Public Health Psychiatry and Co-Director (Emerita) at the HIV Centre and at Columbia University, and Ida Susser is a Professor of Anthropology at the City University of New York Graduate Center and an Adjunct Professor at the Department of Socio-Medical Sciences, School of Public Health, at Columbia University.
For more information and/or comments, please contact Ida at susseris@gmail.com.

Requirement for stronger evidence...

Comment on Stein and Susser

Sharon Hillier and Ian McGowan

The results of CAPRISA 004 represent a major milestone for the HIV prevention field and have brought us to the place that we had long hoped for and all along believed was possible – proof of concept that a topical microbicide, in this case Tenofovir gel, can interrupt HIV transmission in women. But as excited as we all are about these results, proof of concept is not reason enough to declare victory. Evidence about safety and effectiveness must be very strong before any intervention can be considered for widespread use, which is why regulators, including the U.S. Food and Drug Administration (FDA), typically require data from more than one rigorously conducted and well-designed trial.

Although the CAPRISA 004 study was very well done, it was limited in size and it was not developed as a single trial designed to support licensure. Moreover, while the study's results are compelling, they are simply not strong enough to stand alone. The confidence interval surrounding the estimated effectiveness of 39% is quite broad. In other words, Tenofovir gel used at the time of intercourse could be as low as 6% effective or as high as 60% effective.

…women, deserve to have the best possible evidence about the potential benefits and risks of Tenofovir gel…

Indeed, the FDA has made clear that a decision about licensure of Tenofovir gel will depend on the results of a second pivotal confirmatory trial, namely VOICE. VOICE (Vaginal and Oral Interventions to Control the Epidemic) is a study, funded by the U.S. National Institutes of Health, that we are conducting in sub-Saharan Africa. We plan to enrol 5,000 women – 1,000 of whom will be randomised to daily use of Tenofovir gel. We are already near the halfway mark toward completing enrolment and remain on track for reporting results in early 2013.

Photo: AP Photo/Denis Farrell

As researchers and clinicians, we agree with the FDA's requirement for stronger evidence about Tenofovir gel. Importantly, the women in the communities where we are conducting VOICE seem to share this sentiment. They, like all women, deserve to have the best possible evidence about the potential benefits and risks of Tenofovir gel.

Sharon Hillier and Ian McGowan are with the Microbicide Trials Network. For more information and/or comment, please contact Sharon at hillsl@mwri.magee.edu.

Validation is essential...[1]

Comment on Stein and Susser

Mitchell Warren, Emily Bass and Manju Chatani

Can a placebo-controlled trial be conducted in the wake of the CAPRISA 004 findings that the gel reduced HIV-negative women's risk by an estimated 39 percent overall? AVAC believes the answer is 'yes', provided that the informed consent processes for all ongoing and planned trials of 1% Tenofovir gel include explicit explanation of the existing data on 1% Tenofovir gel.

...missing pieces in the process of full, scientific validation of the product and in the regulatory approval process...

This intensive effort to ensure comprehension on the part of trial participants must be backed-up by additional consultations with a range of community groups both in South Africa and in other countries where 1% Tenofovir gel has the potential to be a powerful HIV prevention tool. The substance of these consultations will vary by setting, but should focus on the existing data regarding 1% Tenofovir gel, emerging findings on oral ARV-based prevention, and in gauging and soliciting community understandings and definitions of '*equipoise*' around 1% Tenofovir gel and other forms of ARV-based prevention, and of concerns regarding follow-up studies.

Like many other groups and individuals, including Zena Stein and Ida Susser, AVAC celebrates the news from CAPRISA 004 as a landmark event in the search for new biomedical HIV prevention strategies. The trial provided compelling evidence that the gel reduces women's risk of HIV infection and that this benefit is related to levels of adherence: women with more consistent use of the gel, as measured by self report and returned applicators, had lower rates of HIV infection, than women with moderate or low adherence who also received 1% Tenofovir gel.

Given this evidence that '*the gel works*', why is it ethical to conduct additional trials with a placebo? Guidance on this subject comes from many sources, including the WHO/UNAIDS Ethical Guidance for Biomedical Prevention Trials which states:

> *Researchers, research staff, and trial sponsors should ensure, as an integral component of the research protocol, that appropriate counselling and access to all state of the art HIV risk reduction methods are provided to participants throughout the duration of the biomedical HIV prevention trial. New HIV-risk-reduction methods should be added, based on consultation among all research stakeholders*

including the community, as they are scientifically validated or as they are approved by relevant authorities.[1]

In this instance, the question is whether 1% Tenofovir gel is '*scientifically validated*' on the basis of the data from CAPRISA 004. At this moment, AVAC believes that there are still important questions to be answered about the level of protection provided by 1% Tenofovir gel over time and in different populations, and that these data are missing pieces in the process of full, scientific validation of the product and in the regulatory approval process. These are not academic questions, but are, instead, essential to the process of building a solid, package of information that can be used in regulatory submissions and as the basis of clear, specific communication with potential users.

...ensuring safety and learning more about effectiveness in the shortest possible timeframe...

Given the challenges of introducing and marketing a partially effective product to donors, policy makers, users, their partners, medical providers and all the other stakeholders whose support will be required to realise the benefit of this or any other new intervention, such validation is essential.

If regulatory bodies indicated that they would accept data from a non-traditional follow-up trial, i.e. one that did not include a placebo arm, that would open a new route for proceeding. In the absence of such an indication, though, there is a risk of conducting research that is perceived as leaving doubts or imprecision around the true effectiveness of the product in the eyes of regulatory authorities. (The US Food and Drug Administration has recently stated that it would fast track 1% Tenofovir gel on the basis of data from the ongoing VOICE trial in addition to CAPRISA 004. It is not yet clear what studies will be required by the South African Medicines Control Council to register the product in South Africa.)

Next steps should be taken with the twin priorities of ensuring safety and learning more about effectiveness in the shortest possible timeframe, and with the greatest degree of certainty possible. Assuming that safety and effectiveness are validated, this is the best course for ultimately making this new prevention tool available to all who need it, and to translating clinical trial results into public health impact.

FOOTNOTE:

1. http://data.unaids.org/pub/Report/2007/JC1399_ethical_considerations_en.pdf.

Mitchell Warren is the Executive Director, Emily Bass the Programme Director, and Manju Chatani the Senior Programme Manager at AVAC. For more information and/or comments, please contact Mitchell on mitchell@avac.org.

How much protection is enough...?

Comment on Stein and Susser

The question, 'How much is enough?' *has been a central theme in our efforts to provide women with protection against HIV infection for the past two decades. The idea of promoting a drug, or device, which is not 100% effective at blocking HIV transmission to a woman – or even close – has been highly contentious.*

Erica Gollub

Early studies of '*hierarchical counselling*' on traditional female barrier contraceptive methods that might reduce HIV/STI risks for women, were constructed on notions that '*something is better than nothing*' to give women prevention tools. These studies argued that, in the absence of 100% protection, chipping away at risk must be our goal. Mathematical modelling has borne out this '*risk reduction*' argument; a substantial number of HIV infections in women could result if even a very partially effective drug or device were used widely in the populations at highest risk.

After many years of debate, increasingly lower product effectiveness levels (for example, 30%) have come to be accepted in the microbicide research community as the minimally acceptable goal for pursuing approval of a tested formulation. On paper, then, we have moved a good distance, but the consensus is still shaky. There are multiple fears – that the product will not be used correctly (with women, and vaginally-inserted products, this fear is particularly pronounced with no good evidence to support it); that risk behaviours will change if people believe they are '*protected*' (risk compensation); and that women will be subject to future, physical harms that are not apparent with our current, imperfect set of data. There has been a nagging discomfort with the idea that women themselves should be the ones to choose in the absence of perfect data and a perfect product.

...on paper, then, we have moved a good distance, but the consensus is still shaky...

These fears may explain a large part of the reluctance to move forward with the release of Tenofovir gel, now after the entire spectrum of testing has been completed with the first promising results to come from any microbicide trial to date.

Stein and Susser make a compelling argument for releasing Tenofovir gel for women on the basis that safety concerns have been already evaluated according to standards that are used for other classes of drugs. FDA is charged first with addressing the safety profile of new drugs for approval. Safety concerns in this large-scale, high-quality trial (CAPRISA 004), were virtually

non-existent. The pre-set effectiveness standards of the trial were met. The arguments for continued testing of Tenofovir gel in the context of clinical trials, thus lose their ground, since Phase 3 testing is not the forum for investigating future potential risks in a larger, more general population – the appropriate remedy for the further investigations of different dosing schedules, or extremely rare effects in younger (than 18 years of age) women, is in Phase 4, or drug surveillance phase, post-release. Stein and Susser make careful suggestions regarding important paths to pursue to increase the rigor of Phase 4 activities, citing education and intervention approaches. But certainly, the drug should not be subjected to an even *higher* standard, than any other drug (i.e., repeat Phase 3 testing) in what amounts to a very long debate over magic numbers. The lives of too many women are at stake.

…these fears may explain a large part of the reluctance to move forward…

Experiences with the female condom point to the multiple levels of paternalism in the drug/device regulatory system, and community at large. Regulatory authorities were not sure women could use the device correctly. This device, the first woman-initiated means of protection, suffered absent support from federal agencies and constant lampooning from the media, resulting in widespread negative views among providers and even potential users. These are some of the multiple challenges ahead for Tenofovir gel. Pro-active support and vigorous promotion will be necessary from the AIDS prevention community to support women's adoption, use, and the flow of consistent supplies.

There will never be a consensus on '*how much protection is enough*', because the answer is not – in the main – a scientific one. While we continue to debate these issues, women continue to be infected and die. If lessons from the past decades have any value, we will always have '*potential future harm*' with newly-released products to contend with, but the *present* harm for millions of women, should be where we keep our focus.

Erica Gollub is a Public Health Specialist at the Department of Epidemiology and Biostatistics, Robert Stempel College of Public Health and Social Work, at the Florida International University. For more information and/or comments, please contact her on elgollub@gmail.com.

Confidence limits...

Comment on Stein and Susser

Bruce Levin

We have had many emails questioning our approach to confidence limits and suggesting that we cannot be confident of the results for the microbicide gel. So we asked Professor Bruce Levin, Chairman of Biostatistics at the Mailman School of Public Health at Columbia University.

The question really is, what do confidence limits mean to whom?

If I am initiating a health plan, what are the chances I would reduce the rate of HIV infection, given the statistics on Table 2 of the Karim et al paper (6-60)[1]?

Or, what do they mean to me, a high adherer, if I use the gel and have an expected infection rate of 4.2 (2.1, 7.6) versus if I use the placebo with an expected infection rate of 9.5 (6.0, 13.7)?

Bruce Levin's Answer: Confidence Limits

I think the best way to view a 95% confidence interval is that it tells us what values of the true parameter can be *ruled out* with 95% confidence.

Thus in the first example, where the sample effectiveness was 39% with a 95% confidence interval of (6, 60), I would emphasise that that means we can rule out, with 95% confidence, any *true* effectiveness value less than 6%.

Does that mean 6% should be taken as the best estimate of effectiveness? No. The central value of 39% is the most likely true value. (Technically, and literally, the central value is the maximum likelihood estimate, meaning 39% is that value of the true effectiveness, which would render the observations most likely to occur.)

In the second example, where the sample HIV incidence rate for high adherers was 4.2 infections per woman per year with a confidence interval of (2.1, 7.6), I would again emphasise that we could rule out, with 95% confidence, an incidence rate greater than 7.6 infections per woman per year, with the maximum likelihood estimate of 4.2 as our best estimate of the truth. You can also state that the upper confidence limit of 7.6 rules out our best estimate of the incidence for the placebo gel group, 9.3 infections per woman per year, as a possible true value for the Tenofovir gel group. Similarly, the lower limit of the placebo gel group's 95% confidence interval, 6.0 infections per woman per year, means we can rule out that the placebo group's true incidence rate is as low as our best estimate of the Tenofovir group's incidence rate of 4.2 infections per woman per year.

...the question really is, what do confidence limits mean to whom?...

What should be made of the overlapping confidence intervals for the Tenofovir gel group (2.1, 7.6) and the placebo gel group (6.0, 13.7)? My answer is: use extreme caution here! Just because the confidence intervals overlap does NOT mean

that there isn't a significant difference between the incidence rates for the two groups. In fact, there IS a significant difference between the groups, with $p < 0.03$.

[Explanation: Comparing endpoints of two confidence intervals is a conservative way to declare statistical significance. To declare significance by that method requires a separation between the respective midpoint estimates of 1.96 times the sum of the two respective standard errors. But the correct way to declare significance between two estimates at the 95% confidence level is for the difference to exceed 1.96 times the square root of the sum of the squared standard deviations. It can be shown mathematically that the sum of any two positive numbers is always greater than the square root of the sum of their squares. Therefore requiring two confidence intervals not to overlap is too conservative, and sometimes, as in the case of high adherers, the overlapping confidence intervals does not overturn the statistical significance of the difference.]

FOOTNOTE:

1. Abdool Karim, Q. et al. 2010. 'Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women'. In: *Science*, 2010:329, pp1168-1174.

Bruce Levin, Ph.D., is Professor and Chair of the Department of Biostatistics at the Columbia University, Mailman School of Public Health.
For more information and/or comments, please contact him at Bruce.Levin@columbia.edu.

Images from Vienna...

HIV prevention for women...when?

Comment on Stein and Susser

New data were presented this summer demonstrating the efficacy of an antiretroviral drug-containing gel that can be used intra-vaginally to reduce the risk of sexual transmission of HIV to women.[1] Rightly, the findings were accorded a high prominence at the International AIDS Conference in Vienna in July 2010, and were published simultaneously in the journal Science. *Front page articles in the* New York Times, *amongst others, lauded the study as a breakthrough for HIV prevention.*

Louise Kuhn

Yet, what action has followed from these scientific data? Are there plans afoot to make the gel available to all sexually-active women? Or even to sexually-active women in high prevalence settings, where one in three likely partners will be HIV-infected? Not to my knowledge. The most proactive developments in this field appear to be decisions to continue with already planned, *placebo-controlled*, clinical trials of similar antiretroviral drug products, albeit used in slightly different ways.

Sixteen years ago, the first proof concept that antiretroviral drugs can be used around the time of HIV exposure to prevent transmission was published.[2] These results pertained to perinatal transmission of HIV from mother-to-child and involved a combination of maternal and infant prophylaxis.[3] These results set in motion a scientific agenda that simplified and refined the use of antiretroviral agents to prevent mother-to-child transmission so successfully that some are talking about the '*eradication*' of paediatric HIV infection.[4] Hundreds of thousands, perhaps millions, of infants born to HIV-infected mothers have now been exposed to antiretroviral drugs and tens of thousands, who otherwise would have acquired infection, have been spared this challenging disease.

Initially, a few trials designed immediately after the first proof-of-concept trials were placebo-controlled. This sparked a divisive controversy about ethics.[5] Whatever the merits of the arguments at that time, it would be unthinkable today to propose a placebo-controlled trial of any intervention to prevent perinatal transmission. Today, many studies have been completed examining the safety of antiretroviral drugs for prophylaxis, as well as many studies demonstrating efficacy to prevent perinatal, and now too breastfeeding-associated, HIV transmission[6] among yet-to-be-born and newborn infants – the quintessential vulnerable population. If there are voices raised against the ethics of placebo-controlled trials in women of an already proven intervention, an intervention further bolstered by a substantial body of related research in younger members of the same species, then I haven't heard of them.

...placebo-controlled trials are not necessary for development of appropriate public health policies...

Placebo-controlled trials are not necessary for development of appropriate public health policies, as the example of post-exposure prophylaxis for healthcare workers with occupational exposures to HIV shows. Antiretroviral drugs are routinely given to doctors and nurses with needle stick injuries and other invasive exposures to HIV. A case-control study based on passive surveillance was the basis for these recommendations.[7] For obvious reasons, a placebo-controlled trial has never met with much enthusiasm from eligible participants. Rape survivors, who access better-organised programmes, are also routinely offered antiretroviral post-exposure prophylaxis. I doubt whether even the most brazen '*evidence-based medicine*' fan would argue for the withdrawal of these interventions.

…how do we, as a public health community, trying to be scientifically-informed, but operating with inevitably incomplete and perhaps even flawed data…

Which comes on to the question of pragmatism – how do we, as a public health community, trying to be scientifically-informed, but operating with inevitably incomplete and perhaps even flawed data, take forward new findings that seem to present such promise to do good? Is it by repeating placebo-controlled trials using the exact protocols and reporting requirements of regulatory agencies? Will dogged persistence and attention to bureaucratic minutia win the day? I hope so, because from the data presented from the study in South Africa[8] combined with the existing clinical, epidemiologic and basic science data on the use of antiretroviral drugs to prevent mother-to-child HIV transmission this looks like a winner.

We now know how to prevent HIV in women and the next generation of studies can figure out how to get women to use it. But right now we need to find a way to get it to women.

FOOTNOTES:

1. Abdool Karim, Q. et al. 2010. 'Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women'. In: *Science,* 2010:329, pp1168-1174.
2. Connor, E.M. 1994. 'Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment'. In: *New England Journal of Medicine,* 1994:331, pp1173-1180.
3. *Ibid*.
4. Mofenson, L.M. 2010. 'Antiretroviral drugs to prevent breastfeeding HIV transmission'. In: *Antiviral Therapy,* 2010:15, pp537-553.
5. Lurie, P. & Wolfe, S.M. 1999. 'Science, ethics, and future of research into maternal-infant transmission of HIV-1'. In: *Lancet,* 1999:353, pp1878-1879.
6. Mofenson, L.M. 2010. 'Antiretroviral drugs to prevent breastfeeding HIV transmission'. In: *Antiviral Therapy,* 2010:15, pp537-553.
7. Case-control study of HIV seroconversion in health-care workers after percutaneous exposure to HIV-infected blood: France, United Kingdom, and United States, January 1988-August 1994. In: *MMWR Morb Mortal Wkly Rep* 1995:44, pp929-933.
8. Abdool Karim, Q. et al. 2010. 'Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women'. In: *Science* 2010; 329, pp1168-1174.

Louise Kuhn is with the Gertrude H. Sergievsky Center, College of Physicians and Surgeons; and Department of Epidemiology, Mailman School of Public Health, at Columbia University. For more information and/or comments please contact her on kuhnlou@sergievsky.cpmc.columbia.edu

A careful weighing of priorities...[1]

Comment on Stein and Susser

Tim Farley and Liz McGrory

The results of the CAPRISA 004 trial of 1% Tenofovir gel were greeted with cheers, applause and a standing ovation when announced at the Vienna AIDS conference in July[2]. After nearly 20 years of research, CAPRISA 004 provided the first evidence that the use of a vaginal gel containing an antiretroviral drug (Tenofovir) can prevent HIV infection in women.

The trial demonstrated that 1% Tenofovir gel reduced women's risk of acquiring HIV by 39% compared with the placebo, with the reduction in risk reaching 54% among women who reported using it most consistently. The results were robust and consistent across a range of different analyses, with no apparent safety concerns.[3] The trial marked the first time that a vaginal microbicide has shown effectiveness against HIV in a clinical trial. As such, this represents a major breakthrough in identifying a new method of HIV prevention and a potential new option for women to protect themselves.

There was vigorous debate in Vienna that has continued in other fora on whether or not and how the product can be made available to women most in need, what additional research is required to ensure licensure and effective roll-out, and how the product could best be promoted and distributed. Stein and Susser argue strongly on ethical and moral grounds in favour of rapid roll-out of 1% Tenofovir gel with careful follow-up to monitor for any side effects or other problems. Others have argued just as forcefully that the result must first be confirmed in a further placebo-controlled trial. How can these differing views be reconciled?

There is no single, correct answer to these difficult questions, but a careful weighing of priorities is necessary.

We offer below some additional issues that need to be considered.

Generalizability: The CAPRISA 004 trial was conducted in two communities in KwaZulu Natal, one urban and the other rural. In the absence of confirmatory data, we cannot be

sure that a similar protective effect will be seen elsewhere. Information on the safety, effectiveness and acceptability of the product in other settings with different epidemiologic and social profiles will be critically important before 1% Tenofovir gel is used widely for HIV prevention.

Precision of the estimated effect: The CAPRISA 004 trial showed a 39% reduction in HIV incidence, with a confidence interval ranging from 6% to 60% reduction. While the true effectiveness is most likely near the point estimate, we cannot exclude effectiveness near the lower end of the confidence interval. We need a better estimate of the true effectiveness so that women, providers, and national and international policy makers have a clear idea of the level of protection. This can better inform decisions on how the gel fits into individual and community HIV prevention programmes and strategies.

…we need a better estimate of the true effectiveness…

…a careful weighing of priorities is necessary...

Risk compensation: The potential for risk compensation is a major concern with all new approaches to HIV prevention, particularly those that are partially effective. In the case of medical male circumcision to prevent HIV infection in men, the evidence comes from three independent randomized trials[4], with a pooled effect of 50% reduction in HIV incidence (95% confidence interval 28% to 66%).[5] The lower confidence limit is sufficiently far from zero that modelling suggests that even with very large reductions in condom use there is an estimated net beneficial impact for individuals and communities.[6] During the international policy discussions and efforts to implement medical male circumcision and have an impact on the HIV epidemic, it was clear that there would have been very little interest to implement programmes if the degree of protection had been substantially lower. More and better data than are currently available from the CAPRISA study are required to ensure that the effectiveness of 1% Tenofovir gel is sufficiently large that its overall benefits will not be offset by any potential behaviour changes.

Scale up: The challenges in scaling-up medical male circumcision programmes since the evidence of effectiveness was published in 2007 highlight another compelling reason why stronger data are needed. Despite convincing evidence from three independent trials, a wealth of supporting epidemiological and demographic data and good biological support, progress in medical male circumcision scale-up is lamentably slow.[7] For a new pharmaceutical product the views of national drug regulatory authorities are absolutely critical, as they determine whether or not a product is licensed. But other actors are also critical:

…a potential new option for women to protect themselves…

programme managers must be convinced that a new intervention is feasible, that investing HIV prevention resources in the new intervention will be cost-effective compared with other interventions, ministries of health and finance must be prepared to allocate or re-allocate resources, bilateral and multi-lateral donors must feel confident in the product and that the investment is worthwhile, and individual users must make the effort and commitment to access and use the new product. Unless all these actors are convinced and aligned, the product will fail to achieve the widespread availability and use we all hope for.

…further placebo-controlled studies is essential if the product is to be supported, marketed and used by the large number of women at risk…

So in the context of these uncertainties is it ethical to implement a randomized controlled trial in which some women are allocated the active product and others the inert placebo? Stein and Susser correctly point out that the information provided to participants in future trials must include the new data generated by the CAPRISA study. Previously there were only data from animal models and laboratory studies that the product most likely reduces their risk of HIV infection; now there are also data from women. All research involves a careful balancing of risks and benefits. Frequently the risks are borne by the individual while the benefits accrue to society. However in placebo-controlled microbicide trials there are also well-documented benefits for the individual participant, including improved care, and intensive counselling and help with reducing the risk of HIV infection. In addition, there is an expectation that the product, once shown safe and effective, will be

made available preferentially to former trial participants and their communities. It is the job of independent ethics review committees to ensure that the balance of risks and benefits is reasonable, and the information provided to potential participants is accurate and understandable so that they can make an informed decision whether or not to participate in

the study. If a potential participant is not comfortable with the balance of risks and benefits, she is not obliged to enrol. If during follow-up an actual participant no longer feels the balance of risk and benefits to her is appropriate, she can tell the study team she wants to discontinue.

We are of the view that confirmation of the CAPRISA result in further placebo-controlled studies is essential if the product is to be supported, marketed and used by the large number of women at risk who have few alternative ways of reducing their vulnerability to HIV infection. Exactly what form any confirmatory studies should take is, at the time of writing, being vigorously debated. Key design issues include assessing different dosing regimens, determining safety and effectiveness among women 16 – 17 years old, and expanding the evidence of safety and effectiveness to women living in different epidemiological and social contexts. There will be challenges in planning and implementing such trials, which we must face together if the ultimate aim of the research is to be realised – an urgently needed new tool for women to reduce their risk of HIV infection.

...it is the job of independent ethics review committees to ensure that the balance of risks and benefits is reasonable...

FOOTNOTES:

1. The views expressed are those of the authors and do not necessarily represent those of the World Health Organization.
2. See webcast at http://globalhealth.kff.org/AIDS2010/July-20/Safety-and-Effectiveness.aspx
3. Abdool Karim, Q. et al. 2010. 'Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women'. In: Science, 2010:329, pp1168-1174.
4. Auvert, B. et al. 2005.'Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: The ANRS 1265 Trial'. In: PLoS Medicine 2005; 2(11), e298; Gray, R.H. et al. 2007. 'Male circumcision for HIV prevention in men in Rakai, Uganda: A randomised trial'. In: Lancet 2007:369, pp657-666; Bailey, R.C. et al. 2007. , Moses S, Parker CB, et al. 2007. 'Male circumcision for HIV prevention in young men in Kisumu, Kenya: A randomised controlled trial'. In: Lancet 2007:369, pp643-656.
5. Siegfried, N. et al. 2009. 'Male circumcision for prevention of heterosexual acquisition of HIV in men'. In: Cochrane Database of Systematic Reviews 2009:2, CD003362.
6. UNAIDS/WHO/SACEMA Expert Group on Modelling the Impact and Cost of Male Circumcision for HIV Prevention. 2009. 'Male circumcision for HIV prevention in high HIV prevalence settings: What can mathematical modelling contribute to informed decision making?'. In: PLoS Medicine 2009:6(9), e1000109.
7. WHO/UNAIDS. 2010. Progress in male circumcision scale-up: country implementation and research update. Geneva, Switzerland: World Health Organization and Joint United Nations Programme on HIV/AIDS.

Tim Farley is with the World Health Organization, Geneva, Switzerland, and Liz McGrory is based in Nyack, NY, USA. For information and/or comments, please contact Tim at farleyt@who.int.

Microbicides...[1]
Methods women can use

Ida Susser

Microbicides were the dream of Zena Stein and promoted with Anke Ehrhardt from the Columbia University HIV Centre, which has focused on women since its inception in the 1980s. It was the product of feminist visions and carried through by many more feminists over the last 25 years. Advocates for women pushed for microbicides, when scientists working on AIDS vaccines and treatment had not even envisioned the problem of 'methods women can use'.

...scientific research is only as good as the concepts which drive it...

This example illustrates that scientific research is only as good as the concepts which drive it. No scientific method is the gold standard, no matter how much it is randomised and controlled, if there is no vision behind it that reflects the needs of the affected community. As I have described in my recent book (*AIDS, Sex and Culture: Global Politics and Survival in Southern Africa,* Wiley-Blackwell 2009), feminists have struggled with AIDS research for a generation, trying to frame questions that address women's prevention, safe fertility and breastfeeding. A central aspect of good science is generating the questions that make sense in people's lives. Feminists have had to fight continuously to frame the right scientific questions for women in AIDS. Once we have the questions, we have to generate the best methods to answer them – whether that be a controlled, randomised trial or a qualitative ethnographic case study.

FOOTNOTE:

1. Excerpt from an article published in the *Mujeres Adelante* on 21 July 2010. Susser, I. 2010. 'Finally: A Microbicides Success'. In *Mujeres Adelante*, 21 July 2010, pp1-2. [www.aln.org.za]

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

Why women organise women's organising...

Celebrating 10 years of parallel women's fora

Luisa Orza

The Women's Networking Zone (WNZ) at the XVIII International AIDS Conference (IAC), in Vienna, in July 2010, marked 10 years of women's parallel organising at International AIDS Conferences. The parallel organising that is a regular feature of recent IAC events began at Durban in 2000, when the level of exclusion felt by the local, highly affected community, from the official Conference programme, led to protests and spontaneous organising outside of the conference perimeters.

'*Women at Durban*' was brought about through the cooperation of the International AIDS Society Women's Caucus and the International Community of Women Living with HIV and AIDS (ICW). It facilitated the participation of local women in the conference, moving away from the traditional style of academic and evidence-based sessions, and focusing more on women's own experiences and realities of treatment access, gender-based vulnerabilities, and prevention of vertical transmission, among other issues, narrated and interpreted by themselves. Fittingly, the theme of the Durban IAC was '*Breaking the Silence*'.

10 years on from that first experience, and five IACs later, the Global Village is now an officially recognised community-driven parallel organising space, supported by the International AIDS Society, and dedicated to providing access to, and participation of the local community in the host city of the biennial Conference. The Global Village aims to facilitate dialogue and exchange between the local community and the international delegates. Increasingly it also appeals to an international community of activists,

and represents an alternative conference space not only (or necessarily at all) serving the local community. This lends itself to a less formal style of organising, with a focus on human rights. It centralises marginalised populations and issues; commitment to the meaningful participation of people living with HIV, and the concept that those most affected (by any issue) are those most key to finding solutions; and small-p-political actions, as well as research-and-evidence based conversations.

WOMEN'S NETWORK ZONE...10 YEARS LATER

The Women's Networking Zone (WNZ) convened by The ATHENA Network, has developed as a physical space, political entity, network and social movement since '*Women in Durban*', evolving through Women at Barcelona/Mujeres Adelante ('*Women Moving Forward*') 2002, Women at Bangkok 2004, to the Women's Networking Zone at Toronto, 2006 and at Mexico City 2008, to the WNZ2010 at Vienna, coordinated by ATHENA and the Salamander Trust. The WNZ is now an established element of the IAC, and WNZ2010 constituted one of the largest spaces in the Global Village, comprising an integrated Young Women's Networking Zone and the World Pulse Booth[1], brought about by a partnership of 26 organising entities, with a programme shaped out of over 50 proposals, and incorporating the participation of an estimated 75 different organisations or networks.

The groundwork and organising in preparation for Vienna 2010, led by Tyler Crone of ATHENA Network, Alice Welbourn of Salamander Trust, Wezi Thamm of ICW, and Harriet Langanke of Gemeinnützige Stiftung Sexualität und Gesundheit (GSSG) took months. The five-day event was planned by seven Working Groups, a ten-women Steering Committee, and a four-women Coordinating Team, working between half and full time for four months leading up to the conference. Significant ground-laying preparations included two international meetings, for over a year prior to the event.

...no denying the historical need for parallel (and mainstream) women's organising...

The event itself was managed by a team of approximately 50 voluntary staff, hosts and translators. The ATHENA Network and AIDS Legal Network (ALN) produced a daily newsletter on women's rights and HIV, *Mujeres Adelante,* with further voluntary contributions from WNZ partners and supporters, and produced by a team of women led by Johanna Kehler of the ALN, who worked tirelessly to ensure its daily publication and distribution.[2] Further media efforts were led by Anca Nitulescu, Harriet Langanke and Alice Welbourn, via on-line journals, blogs and press media. The WNZ also provided a host area and supported the efforts of Harriet Langanke of GSSG in piloting a '*Twinning Project*' to bring pairs of women from Germany and countries from Eastern Europe and Central Asia to the conference. The WNZ also saw the launch of Women in Europe and Central Asia Region plus (WECARe+[3]), a network of women living with HIV.

...less formal style of organising, with a focus on human rights...

In short, WNZ2010 was brought about through the enormous efforts of a large number of women, building on 10 years of similar organising, and carried, at least in part, on the tide of that historical momentum. In the meantime, the IAC organising committees have become significantly more inclusive of women; in the lead-up to Vienna 2010, women outnumbered men among the co-chairs of the track committees for the first time ever, and women's organisations were well represented on the Conference

Coordinating Committee. Gendered issues, such as violence against women, sexual and reproductive rights, and sex work, are topics that now regularly appear in mainstream fora, with ever-growing acknowledgement and uptake of gender inequality and human rights gaps and violations as primary drivers of the pandemics. So, while there is no denying the historical need for parallel (and mainstream) women's organising, it is pertinent, in the aftermath of these efforts to ask: '*Do we still need to do this? Why?*'[4]

…that those most affected (by any issue) are those most key to finding solutions…

PHILOSOPHY OF ORGANISING

The WNZ philosophy of organising is based on core themes and principles of feminism, which recognises gender as a central component of relationships of power, rather than an issue of service provision or individual deprivation. In order to acquire a full understanding of how power is organised, it is necessary to recognise and provide space for diversity, the fact that women have multiple identities and huge difference of experiences over time and space, among which interlocking commonalities of experienced oppression may be found. These lie in everyday experience, which feminism recognises as a legitimate source of knowledge, and can be brought to the table through the equally legitimate medium of voice.

Voice acts as the starting point, not for exposure, exploitation and manipulation – as has been seen through the '*using*' of (for example) personal testimony as a means to other, more powerful, groups' political ends – but rather, for an on-going process of dialogue, conversation, linking and informing in progress across time and space.

> *The telling of, listening to, reflecting on, and analysis of personal stories 'from the ground up' are potentially empowering … strategies drawn from women's organizing.*[5]

The structure of sessions in the WNZ is organised around these principles of inclusivity, voice and experience – both through more '*formal*' facilitated dialogue sessions, and more '*interactive*' or story/narrative-based presentations and film/audio documentaries. The design and furnishing of the WNZ are also developed with these principles in mind – there is

no formal stage and participants can sit more informally on cushions on the floor, in circles, and on sofas and/or on chairs if they wish. Thus, through scheduled sessions, targeted informal and formal conversations, and a welcoming space, the WNZ encourages networking, inter-regional, cross-sectoral and cross-generational dialogues, to enable and further women's engagement around women's issues; thereby creating an informal, dynamic and fun atmosphere through which to engender lively, intimate and cutting edge debates.

> *Someone from UNDP on Austrian Radio described the main conference as 'death by power point', which I think is a great description of some of the main conference sessions! A lot of 'talking-at' gets done there, whereas in the WNZ, there is much more engagement between speakers and audience at a much more intimate level.* [WNZ coordinating team member, UK]

At the same time, the WNZ, while welcoming men, recognises the need for women to claim spaces, to organise, and to raise issues without fear of being ridiculed, co-opted or undermined.

> *Women must have a space to organise in order to claim power, as well as discuss their own issues and have important dialogues*. [WNZ presenter, USA]

WOMEN'S SPACES AND VOICES

This strong grounding in feminist themes and principles creates an enabling environment for meaningful participation, developing or deepening a political consciousness, or renewing and revitalising commitment around women's rights issues, which simply acknowledging these issues may not do in and of itself. Issues, such as violence against women and sexual and reproductive rights, have gained a lot of currency over recent years and are edging their way into mainstream fora and agendas. However, these are frequently accompanied by confusing or missing analyses of the issues, leaving women being portrayed as *victims*, lacking in personal agency, or often as agents of reproduction, valuable only as producers of the next generation.

…gender as a central component of relationships of power…

> *I think a lot of the conversations around gender [based violence] are very…it's almost like the AIDS world has hooked into that because it's relatively easy for them.* [WNZ visitor, South Africa]

And despite the rhetoric, women's rights issues *do* continue to be omitted, disregarded, or only partially addressed. In a

recent study[6], researchers found that fewer than a fifth of papers published by the International AIDS Society in two leading HIV journals included research that was clearly relevant to women, often failing to include a detailed gender analysis, disaggregate data by sex, or consider the implications of a problem or proposed solution on women. The WNZ counters this obvious gap, providing what is perceived as a safe space in which to challenge personal/political, public/private dichotomies and grapple with women's rights issues.

> *The opportunity to explore issues, which are key to women's rights and yet are not addressed in the main conference, is essential. As Shirin Heidari, Editor of the IAS Journal said in one WNZ session: 'Absence of evidence does not equal evidence of absence' – and yet many in the main conference often assume that this is the case.* [WNZ coordinating team member, UK]

At the same time, the WNZ tries to keep the level of debate accessible, through a range of comprehensive and coherent messaging and media.

> *I like our zone – the women's network zone – because… all things here have meanings that make a connection to our rights and that we have rights.* [Twinning Project participant, Tajikistan]

Being a woman activist on the international stage of HIV and AIDS is an isolating business; there is no money in it, you are often working on your own and pushing forward an agenda of issues other people would rather not talk about, in an era of ever-increasing resource constraints, and ever-expanding competition for what resources are available. When other marginalising factors come into play, such as living with HIV, being a person who uses drugs or has a '*different*' sexual or gender identity, or who has been in prison, or earns a living through sex work, or, or, or… the stakes are higher and the odds for isolation as a woman activist even shorter.

…women have multiple identities and huge difference of experiences over time and space, among which interlocking commonalities of experienced oppression may be found…

Working in collaboration with positive women's

networks and organisations, the WNZ remains one of the (if not *the*) only significant spaces within the International AIDS Conference that explicitly, consistently and actively promotes positive women's leadership at the same time as celebrating inclusivity and diversity.

> *It is also a safe space for positive women to meet other positive women while not being exclusive to any minority. On the contrary, a space that is open to all diverse groups of women and that is what makes it safe and very important*!
>
> [WNZ steering committee member, Germany]

Workshops, films, story telling/performance narratives, were among the media employed in the WNZ2010 for highlighting issues and challenges faced by women living with HIV, and providing a platform for exchange. The value of hearing the voices of women living with HIV, and creating opportunities to network among women living with HIV, was felt strongly by both HIV positive and HIV negative or untested women participating in the WNZ2010, and also seemed to be an existing and recognised feature of the WNZ. The strong representation of women living with HIV in the Zone *'strengthens women and gives them courage and hope'* (WNZ visitor, UK). It also represents another of the points where the personal and the political meet through the sharing of personal narratives.

> *There is a huge sense of solidarity around universal issues facing us all wherever we live in the world. It is always wonderful to feel that shared sense of identity as women share many 'aha' moments of recognition of one's self in others' stories.* [WNZ coordinating team member, UK]

And, as mentioned above, the creation of an enabling environment for meaningful participation also constitutes an important political commitment and practice.

> *If we are talking about HIV and AIDS (or anything!) the people who are infected and affected need to be given space to speak for themselves, and need to be brought into decision-making and agenda setting in a meaningful way*.
>
> [WNZ presenter, USA]

The potential of positive women's networking was a sub-theme of the WNZ programme, with five sessions that focused directly on the potential of networks of women (including mixed status; HIV positive and HIV negative or untested women) to bring about change. These explored the values, benefits and (potential) outcomes of women's organising through networks, and networks as tools for civil society mobilisation. The realisation of that potential is perhaps the primary objective of the

WNZ as a networking space, linking several of the areas that have been explored above. Networking occurs among individuals, but may have impacts at personal and organisational/institutional levels, and at the level of movement building. At the individual level, networking can be validating and reduce isolation for women activists working in an area that is often little understood and can bring them into confrontational or conflict situations. The WNZ2010 sessions on the launch of the WECARe+ network and the Twinning Project amply illustrate this, and indeed the Twinning Project was conceived precisely to facilitate networking between women who otherwise may have faced an experience of isolation and impotence at the vastness of the International AIDS Conference. The WNZ aims to provide a space that is both stimulating and '*safe*'; welcoming and engaging; and that lends itself to building and deepening dialogue. By reducing the sense of isolation, women are mutually empowered, revitalised and supported to continue their work and expand and deepen their potential as activists and advocates.

> *The WNZ* [is] *a special place…where women from all ages and all countries have a safe space for networking, discuss, engage and feel renovated and re-committed with the response to HIV.* [WNZ programme committee member, Mexico]

Many of the women involved in the WNZ as organisers, contributors, volunteers or visitors are long-term women's rights activists in the field of gender and HIV, and/or international development more broadly. Strong networks and alliances often already exist between them; the WNZ as a physical space at international conferences constitutes an opportunity to strengthen and deepen these alliances, networks and friendships. However, the WNZ continues to attract new visitors, presenters and supporters, in part due to the change in regional and thematic focus brought about by the different conference locations; in part due to advances and emerging issues in the field; and in part due to

…either no laws that protect women from violence, or where laws exist the mechanisms are inadequate to enforce their implementation…

a growing recognition of the gender drivers of the epidemic and the increasingly urgent need to address these.

After 10 years of women's organising at the IAC, the WNZ as it stands today represents something beyond a networking event or partnership, but now lies at the heart of movement-building around women and HIV – by bringing together women from networks, organisations, agencies and institutions working on similar topics; through deliberate efforts to create continuity from one WNZ event to the next; and by maintaining links and collaborations and the '*conversation in progress*' working through the ATHENA Network and other global and regional networks and listservs.

…by reducing the sense of isolation, women are mutually empowered, revitalised and supported to continue their work and expand and deepen their potential as activists and advocates…

The principle of local organisation around the WNZ ensures that the drive and leadership of each event is taken-up by different organisations and individuals at each conference. Previous coordinators or partners lend experience, guidance and input into the process, thereby building always on what has gone before and strengthening the movement with both new and longer-term partners.

The principle of consultative process means that planning for the next conference begins almost immediately after the end of the previous one, opening up an 18-month-to-two-year period over which new alliances are consolidated around the WNZ and the movement kept alive.

So are these processes and efforts of organising still worth it? From the responses to WNZ2010: A resounding *YES*!

Keep this space – there's nothing else like it here!

[WNZ visitor, anonymous]

FOOTNOTES:

1. World Pulse is a 3,000-strong on-line community forum that looks at global issues through the eyes of women. For more information go to www.wordpulse.org
2. To obtain copies of the *Mujeres Adelante* edition, please go to www.aln.org.za.
3. For more information on both the WNZ and WECARe+ go to www.wecareplus.net or www.womeneurope.net
4. Italicised quotes used in the remainder of this article are taken from questionnaires and interviews used in the evaluation of the WNZ2010, unless otherwise attributed.
5. Maguire, P. 2001. 'Feminisms and Action Research'. In: Reason, P. & Bradbury, H. (Eds) 2006. *Handbook of Action Research*, Sage Publications, London, p64.
6. Collins, E., Hale, F., Gahagan, J., Binder, L. & Crone, T. 2010. 'Gendered Neglect: How relevant is HIV research to women?'. Poster Presentation 6172, International AIDS Conference, Vienna 2010.

Luisa Orza was a joint coordinator of WNZ2010 as a Salamander Trust Associate with Amandine Bollinger of Salamander Trust. For more information and/or comments, please contact her at luisa.orza@gmail.com.

Meet women where they live...[1]

Creating a meaningful, effective AIDS response for women

HIV and AIDS have been part of the global landscape for nearly 30 years, and will continue to impact the lives of millions of people, particularly women and girls, far into the future. Policy makers, programme managers and service providers have long been aware that women and girls are uniquely vulnerable to HIV infection.

Sarah Degnan Kambou, Katherine Fritz, Reshma Trasi

Social science research conducted across the globe describes how the underlying causes of poverty and gender inequality heighten the vulnerability of women and girls to HIV. Faced with high rates of violence, poor access to school, health information, or legal services, women and girls are often at a disadvantage when managing their risk to HIV.

Global funders recently called for a more efficient use of resources to better serve the healthcare needs of women. They advocate integrating HIV prevention and treatment services with other reproductive health and family planning services. This is a highly desirable goal. Yet, even if countries improve their health systems, this alone will affect only certain aspects of women's vulnerability to an epidemic fuelled by underlying legal, social and economic inequality.

More must be done. We believe that a meaningful, effective AIDS response, at its core, demands an understanding of how women live. Here are our recommendations:

- ***Understand who women are and what they need***. Services often focus on women's singular needs, such as food or livelihoods, or their singular identities as mothers or sex workers. They are women *and* mothers. They are sex workers *and* loving partners. They are at risk of hunger *and* HIV.
- ***Craft a response that recognises that women live every day in relationships*** with families, communities and institutions – connections that influence their HIV risk.
- ***Let women speak for themselves and articulate their needs***. This means intentionally placing women in leadership positions – especially those living with HIV – on national and international decision-making bodies, as well as ministries and committees that address issues affecting women.
- ***Make policies work***. National HIV responses must have a multi-faceted vision that truly addresses women's needs. Government leaders must mandate, coordinate, fund and be accountable for strategic plans that ensure women's right to full, healthy lives.

It's time we did better by women. Let's get it right – right now

FOOTNOTES:

1. An earlier version of this article was published in the *Mujeres Adelante* on 18 July 2010. Degnan Kambou, S., Fritz, K. & Trasi, R. 2010. 'Meet women where they live: Creating a meaningful, effective AIDS response for women'. In: *Mujeres Adelante*, 18 July 2010, p2. [www.aln.org.za]

Sarah Degnan Kambou, Katherine Fritz and Reshma Trasi are from the International Centre for Research on Women (ICRW). For more information and/or comments, please contact Reshma at rtrasi@icrw.org.

A new network for positive women...[1]

Luisa Orza

'I'm surprised to be sitting here alone', *said a bemused Andrea von Lieven, from the speakers' couch at the launch of a new network for Women living with HIV in Europe and Central Asia (WECARe+) on 20 July 2010.*

But her short-lived solitude also spoke to one of the needs behind the network.

Women who live openly with HIV get pulled in so many different directions – especially at conferences like AIDS2010.

Happily, Andrea was soon joined on the couch by positive women from Romania, Ukraine, Italy, The Netherlands, the UK, and Germany.

WECARe+ is the brainchild of Harriet Langanke, director of the German organisation GSSG: Gemeinnützige Stiftung Sexualität und Gesundheit (Charitable Foundation Sexuality and Health), and positive activist Wezi Thamm. Their efforts were supported by Abbott Pharmaceutical Company, who have funded the registration of the network and enabled the set-up of the seven-language Women in Europe website (www.womeneurope.net), which will provide vital on-going communication support to the network.

The fledgling network has ridden on the tide of momentum generated by AIDS2010, but the conference is just a start. It is important that the network has its roots grounded in real need, commitment and vision for the network to carry this work forward. So what do women want from the network in the future?

'*I would like this organisation to help us to not be invisible any more*', said Silvia, a positive woman originally from Mexico, now living in The Netherlands, '*so that women be included and participate in decision-making and policy-making*'.

Isabelle Nunez spoke about the need for solidarity and support among women living with HIV, which in lower prevalence countries is not always easy to find. '*I'm the only openly positive woman with a public position in Portugal and I feel alone*'. Conferences provide a rare opportunity for Isabel to work side-by-side with other positive women.

> *I came here and there was Wezi and other women who support me and I felt, oh, I'm ok now. That's what networks for positive women are for.*

...the conference is just a start...to help us to not be invisible any more...that's what networks for positive women are for...

Silvia Petretti, an Italian activist now living in London has been closely involved in the start-up and development of PozFem UK – the UK network of women living with HIV since 2004.

> *Women's networks are incredibly important at so many levels. Once you have support from other women in your same circumstances, you find the strength and inspiration to move on and become vocal, to become advocates and to stand-up and claim your rights – and that's crucial if we want to create a world where we are visible and to reduce stigma and discrimination* – says Silvia.

The need for such a movement to support women living with HIV across Europe has been born by the initial findings of a survey carried out among positive women living in Europe and Central Asia over the last few months to gain a better understanding of how the epidemic is playing out in the region. Of the 165 survey respondents, only 14% were living openly with HIV; 54% had received no counselling upon receiving their HIV positive diagnosis, including 43% of the English-speaking respondents; about a third of the women had experienced some form of gender-based violence; and only half had chosen to reveal their status to their partner.[2]

The more qualitative elements of the survey produced evidence of a range of mental health issues and lack of support to address these. But they also spoke about a range of tools and resources for overcoming these challenges, which underline the need for networks. One German speaking participant sums it up:

> *The most support I got was from other people living with HIV.*

FOOTNOTES:

1. An earlier version was published in the *Mujeres Adelante* on 21 July 2010. Orza, L. 2010. 'Women's Realities: A new network for positive women in Europe and Central Asia – WECARe+'. In: *Mujeres Adelante*, 21 July 2010, p4. [www.aln.org.za]
2. Further results from the survey can be found on www.womeneurope.net.

Luisa Orza is a women's rights and HIV activist and the WNZ coordinator. For more information and/or comments, please contact her at luisa.orza@gmail.com.

The power of organised communities...[1]

Legislating sex work

Kate Griffiths

Sex work advocates gathered today in a mini-session to assess the impact of sex work legislation both in countries around the world and across time. In a historical overview by the Lawyers Collective's Tripti Tandon, it became clear that throughout its history, sex work legislation has been determined less by results than by political pressure, and has a long history of being tied to gendered moralities, public health, feminist concerns, and drug use.

Today's sex work legislation is no different, with evidence about effectiveness often taking a backseat to fears of trafficking, conservative religious morality or misguided efforts to protect victims of trafficking and violence. Drawing on evidence from British history, as well as the experiences of sex workers and sex work organisations in India, China, the UK, New Zealand and Sweden, the panellists argued that decriminalisation and sex workers' self-organisation is the most effective model for halting the spread of HIV, as well as for protecting the human rights of women and sex workers.

Tandon traced the history of sex work legislation back to Cannon law of the Catholic Church, which considered prostitution a sin, like all sex outside of marriage. Criminal penalties did not apply, however. With industrialisation in England, public order became a concern and a '*crackdown*' on street workers and so-called '*bawdy houses*' represented the first criminalisation of sex work. In the 1860's this model was replaced with a public health focus as the military became concerned with protecting

the health of soldiers, and therefore passed several iterations of the Contagious Diseases Act, which implemented mandatory testing and imprisonment in hospitals for sex workers. Not long

after, these regulations came under attack by feminists of the age, not for violating the rights of sex workers to consent to medical treatment and testing, but because by regulating sex work, advocates felt that the government was sanctioning abuse and violence against women. Ultimately, the law was repealed and replaced with codes based on strict Victorian morality, which resulted in greater stigmatisation, clandestine work, and pimping and police abuse of sex workers.

Today, sex workers' rights face similar foes and sex work legislation produces similar results. In the last few years, not only some feminists, but also some religious communities have rallied opposition to *'trafficking'* or non-consensual sex work, involving the kidnapping of foreign women. While sex worker organisations argue that trafficking is rare, such campaigns can result in the adoption of harsh legislation that makes sex workers more vulnerable to HIV, but also to homelessness, rape, and poverty.

…decriminalisation and sex workers' self-organisation is the most effective model for halting the spread of HIV…

Global Fund researcher Swarup Sarkar has identified three kinds of strategies that can reduce HIV transmission via sex work (which he argues is the most cost-effective point of intervention.) These include state-led punitive measures, such as seen recently in Thailand and the Philippines; NGO-led service delivery; and finally sex worker self-organisation as seen in India. Of the three, long-term improvement in infection rates have been achieved only through the latter, supporting activists' contention that criminalisation and punitive approaches do not achieve public health goals. In one example from Norway, self-organised sex workers were able to reduce the spread of a virulent strain for herpes by temporarily halting sexual practices, such as protected oral sex, until the outbreak subsided.

…criminalisation and punitive approaches do not achieve public health goals…

In China, where sex work legislation is draconian, calling for punishment of forced labour, sex workers from Phoenix in Yunnan point out that criminalisation of drug use is also a major factor in isolating sex workers in ways that increase their vulnerability. Drug users there face mandatory HIV testing at random and are particularly vulnerable to police abuse, if they are migrant workers, who are thus unregistered in the province.

In the modern day UK, a new wave

of punitive legislation targets clients rather than sex workers, reminiscent of the *'Swedish model'*. These laws nevertheless have similar impacts on sex workers to the older versions of the 1860's forcing women into street work by criminalising landlords and to greater clandestine work making them more vulnerable to violence, including rape. This vulnerability has been demonstrated in a string of murders of sex workers known as the Bradford murders. According to Pye Jakobbsson, the '*Swedish model'* in Sweden has a similar effect. One friend and street worker, she mentioned, claimed that *'before the law I was never raped. After the law, I can't count the number of rapes*'. Despite arguments that the law protects women, women find little support from the police and experience increased stigma.

An alternative to models which criminalise clients is decriminalisation, as practiced in New Zealand since 2003. Presented by Tim Bennet, former NZ parliamentarian, the impact of the law, which legalises sexual contact between consenting adults, is increased safety, condom use and lowered risk of spreading HIV.

Achieving decriminalisation required cooperation between sex workers, feminists, LGBTQ organisations and health officials, as well as members of parliament. As the history of such measures and the epidemiology of health and sex work demonstrate, it is the power of organised communities, not merely great evidence, that can achieve good law, better health and secure the rights of women and sex workers.

FOOTNOTES:

1. An earlier version was published in the *Mujeres Adelante* on 23 July 2010. Griffiths, K. 2010. 'Special Report: Legislating sex work'. In: *Mujeres Adelante*, 23 July 2010, pp6-7. [www.aln.org.za]

Kate Griffiths is a writer and ethnographer based in Durban, South Africa. For more information and/or comments, please contact her at kategrif@gmail.com.

Women ARISE!

Strengthening the women's agenda at AIDS 2010

The Women ARISE (WA) *coalition, made up of a diversity of 39 women's/AIDS networks and organisations from all regions of the world, was created to increase the visibility and presence of the diversity of women and girls, and to bring their voices and perspectives to Vienna 2010.*

Mabel Bianco

The networks and organisations brought together by the coalition represent diverse collectives of women, including women living with HIV, sexual and reproductive health and rights, human rights and especially women's rights activists, sex workers, female youth and adolescents, drug users, lesbians and transgender and transsexual people.

The Vienna conference aimed especially to highlight the critical connections between HIV and human rights, so its slogan was '*Rights Here, Right Now*'. WA used this theme to call specific attention to the human rights of women and girls, developing and promoting a full agenda of activities that brought women's and girls' issues and voices to the heart of the conference.

As a result of WA's advocacy during the organisation of the conference, one of WA's most important achievements was the incorporation of women speakers with a gender perspective in all areas of the conference programme and the achievement of a gender balance of speakers in almost all the sessions. In the Plenary sessions alone, half of the speakers were women and the proportion of women speakers representing women's perspectives in other sessions was almost as high, averaging forty percent.

Another important achievement was the thematic balance of the sessions, with greater inclusion of women's issues than in previous conferences. The issue that received the greatest attention was women's sexual and reproductive health and rights. Another success of WA was to incorporate violence against women as a plenary session theme, as well as in many other sessions, and to appoint as speakers many feminist women with a gender perspective altogether with human rights experience – a '*novelty*' in these conferences. Although '*abortion*' was only addressed in a few sessions, even this marks a great achievement since it had never been incorporated before, but it needs to be strengthened in the next conferences. However, lesbians and women who have sex with women (WSW) were still not incorporated

into the main conference programme, but at least we were able to incorporate a session in the Human Rights Networking Zone, which is not sufficient. These are persisting gaps that represent future challenges for the women's constituencies in WA and demonstrate how we must continue to broaden the agenda for women and girls at future conferences.

…the incorporation of women speakers with a gender perspective in all areas of the conference programme and the achievement of a gender balance of speakers in almost all the sessions…

The activities developed by WA at the conference, starting prior to the opening on the first day, gave a high level of visibility to women for the rest of the week. On July 18, a large group of women, using WA t-shirts and posters, held a demonstration during the Opening Ceremony where they demanded: '*Women's Rights, Action Now!*'. WA also had an important presence in this ceremony, as well as in the plenary sessions and the closing session, through the participation of coalition members as speakers who excellently expressed the perspective of women and women's rights issues at the centre of WA's position. They included *Rachel Arinii* (ARROW) as young women's representative and *Paula Akugizibwe* (ARASA) in the Opening Ceremony, *Everjoice Win* (Action AID International), and *Meena Seshu* (SANGRAM) as plenary speakers, and *Patricia Perez* (ICW Global) as speaker in the closing ceremony.

The special session organised by Women ARISE on the opening morning of the conference: '*Women's and Girls' Issues at the Vienna Conference*', was a mechanism to strengthen the agenda and alliances, and strategise before all the conference activities began. The invited speakers each had a special significance for the women and HIV agenda: Dr. Nafis Sadik, the former leader who, as Executive Director of UNFPA made the International Conference of Population and Development, known as the Cairo Conference, possible, which, for the first time, recognised sexual and reproductive rights, paying special attention to HIV, particularly for women; Purnima Mane, as an expert and a woman committed to sexual and reproductive health and HIV, and now as Deputy Executive Director of UNFPA, is one of us opening opportunities for women and girls. Christoph Benn represented the Global Fund to Fight AIDS, Tuberculosis and Malaria and, as an organisation with a Gender Equality Strategy and Sexual Orientations and Gender Identities (SOGI) Strategy to integrate gender equality in the HIV and AIDS response, had the opportunity to come to know WA and our interests and ideals; Dr. Michel Sidibé, because his leadership made possible the Operational Plan for the UNAIDS Action Framework on Women, Girls, Gender Equality and HIV, and because we need the continued commitment of UNAIDS for its urgent implementation so that women and girls are put at the centre of the HIV response. The participation of these leaders in the session, as well as that of many WA members was important for giving urgency to the incorporation of women's and girls' issues into the HIV response, and also showed the political importance of WA being able to build alliances as a strategy to achieve our goals.

Women ARISE organised and participated in a wide diversity of sessions during the conference, including a session '*The invisibilisation of lesbians and WSW in the HIV/AIDS epidemic*' in the Human Rights Networking Zone, as well as several

sessions addressing the issue of abortion in the framework of reproductive rights, especially from the perspective of women living with HIV. In all these sessions, diverse women from all regions of the world made their voices heard.

WA also had a booth in the Commercial Exhibition Area of the Conference that was used as a showcase by the different women's groups in the coalition to make their messages and demands visible through posters and activities that went along with the daily themes of women living with HIV, sex workers,

women '*victims*' of violence, lesbians, young women, women who use drugs, and women activists on sexual and reproductive health and rights. In the booth, the *Daily Vulva Award* was used as a way of calling people's attention to women's interests and issues, as well as our demands and needs, and also for decoration to make women's bodies visible. This was very controversial, because of its relation to sexual pleasure, which is still largely questioned for women around the world.

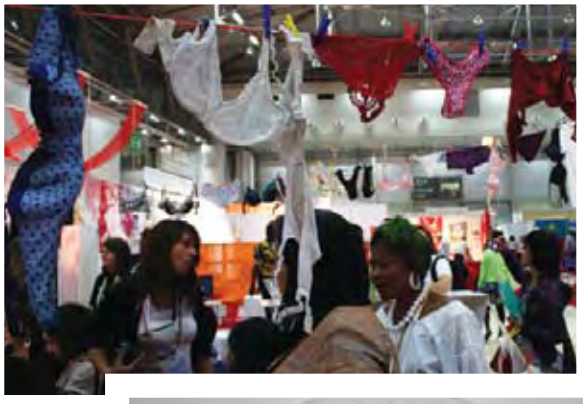
Although Vienna 2010 marked many achievements for the inclusion of women and women's issues in the conference, persisting gaps were identified, especially in regard to some neglected issues, such as the incorporation of lesbians and WSW in the response to the epidemic, as well as abortion, ARV dosages and their effects on women.

...persisting gaps were identified, especially in regard to some neglected issues, such as the incorporation of lesbians and WSW in the response to the epidemic, as well as abortion, ARV dosages and their effects on women...

These issues, and also how to strengthen women's presence in all their diversity, are challenges that Women ARISE and its constituencies must work together to overcome by pushing for a broader agenda for women and girls at Washington 2012. We are committed to continue working until Washington 2012 and beyond.

Mabel Bianco is with Women ARISE.
For more information and/or comments, please contact her at womenarise@aidswomencaucus.org.

Messages from Vienna...



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