In Focus...
The challenges of prevention and covering the cost...

Two presentations at Tuesday’s plenary integrated comprehensive visions, while maintaining a keen eye for how their conclusions could or would be implemented to make tangible differences in the real lives of the people and communities they affect. The final presentation outlined the contributions of the Obama administration in the development of a US National HIV/AIDS strategy and the creation of the Affordable Care Act.

Dr. Nelly Mugo’s presentation reflected a grounded understanding of women’s issues and made clear that in many parts of Africa, the epidemic is very much about family life and children. She pointed out that in Kenya, 44% of new infections are among married and cohabiting couples. In addition, 50% of partners are sero-discordant and many do not know their status. She also noted that among many couples, the desire for children overshadows the fear of infection, leading to further infections. In addition, while 42% of new infections worldwide are among youth 15-24, 80% (4million) of these are in sub-Saharan Africa, where young women infected with the virus out-number men by two to one.

Having outlined the shape of the epidemic in Kenya and many parts of Sub-Saharan Africa, Dr. Mugo considered where the new prevention opportunities might be useful. As researchers have been reminding us throughout this conference, PrEP (treating uninfected individuals to prevent infection), and early treatment, no matter how successful in experimental situations, only work when they are taken. For this reason, Mugo insisted that all interventions must have a behavioural arm and, more importantly, that any interventions must be owned by communities to be successful. She gave the example of the Luo Council of Elders, which endorsed male circumcision and led to a popular acceptance of the procedure in Kenya in contrast to other regions, where the introduction was less effective. In general, Mugo argued that the process of prevention must be multi-faceted and be discussed and adopted by the communities themselves.

Mugo emphasised that effective prevention must involve male circumcision, treating STIs, condoms, Tenofovir gel and many other tools. However, she saw a role for the use of PrEP, for limited time periods: perhaps among high risk youth aged 16-24 or among discordant couples when they want...
to conceive. She also suggested that PrEP might be useful for vulnerable populations, such as couples in situations of intimate partner violence or even people in conflict zones. However, it would be precisely in these situations that adherence would be most difficult. Patient empowerment, support groups, and testing linked to services and the home delivery of pills might help to foster adherence in such difficult circumstances.

Dr. Berhard Schwartländer, the Director of Evidence, Innovation and Policy at UNAIDS, offered an insightful and well-organised presentation of the changing global economic scene and its impact on the world community’s response to the AIDS epidemic. In years past, he noted, we spoke of wealthy countries and poor countries, in a paradigm of charity and need. Today, however, we operate in an international economic climate where many lower income countries have experienced unprecedented development sufficient to change the conversation on resource allocation. Schwartländer was, however, careful to note that while there has been financial progress in parts of the developing world, the wealth produced has not been well distributed. As one slide illustrated, for example, despite a doubling of GDP in South Africa over a given period, the income of the poorest 20% has remained stagnant, a difference that is likely even more striking amongst women. This uneven progress exacerbates inequality, a well-established social risk factor for HIV.

Schartländer also discussed alternative modes of funding for this new global economic order. Rather than the old charity-based conception, he envisions a world where middle-income countries take control of their epidemics through comprehensive funding initiatives, some independent and some in partnership with the international community. Some foreseeable fundraising tactics he described included various tax-based programmes focused on international commerce, with revenue ear-marked for HIV spending.

While much of the talk focused on fiscal realities, Schwartländer did not neglect the socio-political and human aspects of HIV prevention and treatment. In one comparison of the AIDS response in Brazil and Russia, he demonstrated that in these two countries of similar population, epidemic severity and GDP, Brazil achieved far superior results than did Russia. Schwartländer attributed this difference to Russia’s refusal to address human rights issues, especially with regards to the epidemic amongst IDU and MSM populations. Schwartländer presented a salient and empowering vision for a financially changing world, but until that vision includes an explicit understanding of the challenges facing 21st century women, it will remain incomplete.

It was particularly cheering at the end of the plenary session this morning to be reminded by the Assistant Secretary for Health, Howard Koh, of the ways in which the Affordable Care Act, such a long fought and still fraught battle, will make life easier for people with HIV. From January 2014, insurance companies will not be allowed to refuse adults insurance because of pre-existing conditions. In addition, as the Act goes into effect, insurance companies will no longer be allowed to cap expenses for care. Although we did not win anything like what we need, the Affordable Care Act is a landmark in the provision of healthcare nationwide, and will be particularly significant for people living with HIV, specifically for women who predominate in the jobs without health insurance or benefits in this country.

Ida is a professor of anthropology and Zena is an epidemiologist of Columbia University.
News from the Global Village…

Meaningful involvement in research…?

Doris Peltier illuminated the unique position aboriginal women in Canada face in terms of involvement in research methods during the session Meaningful Involvement of Women Living with HIV: Women-specific Community-based Research Model. Peltier’s perspective on HIV research, cultural insensitivity, and questionnaire rhetoric offers a multi-dimensional look into the changes that need to be made in community-based research practices.

As an aboriginal woman living with HIV, Peltier outlined her concerns with the treatment of her community in research. Every time Peltier is asked to participate in research, she questions why she is approached to be involved because, as she puts it, ‘we’ve been researched to death’. Many questionnaires are insensitive to cultural backgrounds of aboriginal women living with HIV in Canada. Even the term ‘aboriginal’ is used to describe a community of indigenous women that is composed of over 200 nations within the indigenous community. But for health service, government, and research-intensive purposes, the nations are grouped together under one banner, further demonstrating the dismissal of cultural backgrounds. This ‘one-brush-stroke’ approach to research also leads to tension and mistrust between women and the researcher.

Peltier believes it is important to emphasise the qualitative approach to research, instead of quantitative, as women’s voices are limited in quantitative methods and only produce a ‘snap shot’ of women’s realities. Qualitative research however empowers women to articulate their voices and experiences.

Finally, when research is released, Peltier criticised the sensationalised rhetoric usually used to describe the findings. Rhetoric, such as under-served, marginalised, vulnerable, injecting drug user, disproportionate, uneducated, and poverty are commonly presented in association with statistics about HIV in the aboriginal community. She admits that although the statistics in reality may be alarming, these sensational words used in research documents do not describe numbers or statistics, but actual people and communities. The use of the vindictive language ‘tells a very dangerous story’. She questions, if this language is beneficial or instead the new language of racism, paternalism and colonialism?

News from the ‘margins’…

Moving forward on transgender vulnerability to HIV

Transgender people are acknowledged as a most at risk population. At AIDS2012, there have been several sessions addressing the issues of transgender people in the HIV pandemic, and several transgender people have presented on the diverse issues that they face in their communities, ranging from violence and discrimination, to a lack of access to information and services. Interestingly, these sessions have been speaking specifically to transgender issues, not simply in the context of MSM; an improvement over previous conferences, especially since they took place at the main conference, not the Global Village. However, it still seems that the issue is still largely considered to be transgender women’s issues, as the voices of transgender men have barely been featured. Furthermore, the absence of so many sex workers from the conference also means the absence of many transgender people from across the world, as many transgender people resort to sex work, due to their socio-economic position in societies where people who transgress gender norms are severely stigmatised.

Sessions addressed the vulnerability of transgender people, the violence that transgender people all over the world face, and how access to services in any country has still not been realised. There is, unfortunately, little emphasis on intersections of these vulnerabilities. Transgender people face violence and discrimination, due to gender-based stigma, the violence they face is gender-based, and the basis of their vulnerability is not isolated from the vulnerability that women in general face.

In order to truly address the structural issues that fuel the HIV pandemic, we need to think further than populations, or treatment and care; we need to consider the human rights issues that most at risk populations face, and understand that these are interlinked, and often gender-based.

Transgender rights benefit not only transgender people; they challenge the gender norms that fuel vulnerability for women in general.
A n excellent panel on the criminalisation of sex work on Monday boasted contributors from all over the world, documenting the similar legal problems facing sex workers in various countries, despite differing legal frameworks. Globally, sex workers face both prosecution, coercion using threats of prosecution and marginalisation from fear of prosecution, as well as from migration status, and intersecting forms of oppression, such as gender-based violence and stigma against ‘queer’ and transgender people.

Presentations by Wen Zhai of China, Laurent Geffroy of France, and Hajdi Shterjova Simonovikj of Macedonia highlighted the often contradictory, competing and confounding relationship between law enforcement and public health measures as search, detention, fines and imprisonment prevent sex workers from seeking healthcare or make them suspicious – often justifiably – of medical outreach workers, clinic staff and health officials. Wen asked poignantly, whether governments and public health policy makers ‘are not making the same mistakes?’ with sex workers as those recognised and condemned by IAS in Vienna in 2010 with regard to drug users.

While the session provided insight into these shared experiences of sex workers worldwide, it also highlighted criminalisation, stigmatisation and marginalisation by local and national authorities in the United States. The panel included an informal remote presentation by a sex worker from Calcutta whose presence in absentia (and official exclusion from the panel and programme) reflect the impact of the ongoing U.S. travel ban against sex workers and drug users. As the panel chair noted – losing the voice of sex workers from outside the US at this conference deprives delegates of nuanced understandings of the interplay between criminalisation, marginalisation and its effects, including addiction and violence.

Megan McLemore of Human Rights Watch (HRW) also expanded on the theme of criminalisation and marginalisation in the U.S. by presenting the findings of a recent HRW report focusing on four major cities; Washington D.C., New York, Los Angeles and San Francisco. The report meticulously documents the widespread practice of police using condoms carried in a purse or elsewhere as evidence of illegal sex work, often threatening to arrest sex workers carrying condoms, and sometimes doing so. As a result, many women and other workers believe it that it is illegal to carry a certain number of condoms – or any at all! This police practice therefore undermines public health efforts in these cities to distribute condoms and promote safer sex among sex workers and among transgender women.

Women’s Realities…
Criminalising sex work…
Human rights abuses in the United States

...undermines public health efforts in these cities to distribute condoms and promote safer sex among sex workers and among transgender women...

Kate is an anthropologist and writer, who lives in Brooklyn, NY and frequently works in Durban, South Africa.
Are women and gender still on the agenda at the Global Fund?

Kate Griffiths-Dingani


The ambitious plan would see the Global Fund get behind proposals that could scale-up services and interventions that reduce gender-related risks and vulnerabilities to HIV infection; those that would decrease the burden of disease for women and girls most at-risk, such as women using users, sex workers and adolescent girls; proposals that would mitigate the impact of HIV, TB and Malaria, as well as programmes that would address structural inequalities and discrimination against women. This strategy seemed to be a crucial step on the road to ending gender-blindness in the institution, and a process whereby prevention and treatment strategies with the potential to harm women and girls could be identified before they are implemented. The strategy is particularly challenging in that it asks a funder that deals primarily with biomedical interventions to bring the same rigor to social and cultural aspects of treatment and prevention.

As the strategy was being developed, The Global Fund started to feel the effects of the globally uncertain financial climate. After failing to meet funding targets, the Global Fund both scaled-back on some grant making, as well as suspended a round of grants in 2011.

That same year, two years into the new gender strategy, its success in terms of being implemented was reviewed by neutral outside evaluators. The resulting report by the Pangaea Global AIDS Foundation indicated that, according to major stakeholders in the fund’s process, there was still a long way to go in terms of both remaking the institutional ‘lens’ into one that could identify harmful gender bias, as well as proposals likely to successfully impact women and girls most likely to be infected and affected by HIV.

The Global Fund responded positively to the constructive criticism, but released a statement in which it’s gender focus was restated in a way that advocates interpreted to be a narrowing of emphasis. The Secretariat would now focus grant making on prevention of mother to child transmission and maternal, new born and child health; the prevention of gender-based violence and harmful gender norms; and most at risk populations of women, specifically female sex workers and women using drugs. This new, more focused scope is problematic, not least because two of the three areas of work replicate focus from elsewhere in the Global Fund’s agenda, and because too often ‘mothers’ remain the forgotten aspect of ‘maternal child health’, while women who are not mothers are excluded entirely.

Yesterday, activists and Fund staff met in the Women’s Networking Zone to brainstorm next steps on moving the gender agenda forward at the Global Fund. In addition to the economic environment, the participants identified challenges, such as developing national strategic plans for HIV and AIDS that go beyond lip service to gender equality. They discussed the need to develop the capacity of women’s rights organisation around the globe, as well as the need for successful models of gender-aware policy on HIV.

Despite the increasingly austere grant making environment, advocates for the rights of women and girls will continue to call for the full implementation of the comprehensive gender strategy by the Global Fund and by similarly situated organisations and institutions. The economic crisis makes this task more difficult, but it also more needed, as increasing numbers of women worldwide now live in poverty, exacerbating their vulnerability to HIV, TB and Malaria.

Kate is an anthropologist and writer, who lives in Brooklyn, NY and frequently works in Durban, South Africa.

UPCOMING EVENTS

Wednesday, 25 July

07:00-08:30 Messages that Matter: Reaching the World’s Women with Effective, Evidence-Based HIV Prevention Strategies Mini Room 3

08:40-10:30 Plenary: Turning the Tide on Transmission Session Room 1

10:30-11:30 At the Centre: Intergenerational Dialogue on Young Women’s SRHR in the context of HIV WINZ, Annex

11:30-12:30 Positive Women: Reducing Vulnerability and Reinforcing Empowerment Opportunities Session Room 2

11:45-12:45 Pregnancy Intentions of HIV-Positive Women: Forwarding the Research and Advocacy Agenda WINZ

12:45-13:45 Lunch

14:30-16:00 Hormonal Contraception and HIV: An Evolving Controversy Session Room 3

14:30-16:30 Turning the Tide for Women and Girls: How to Advance Positive Women’s Leadership and Advocacy for HIV Action in One-Minute Mini Room 5

15:30-16:30 Ensure that women’s voices are heard: Barriers to Women’s Access to Prevention of Vertical Transmission Programmes WINZ

16:30-18:00 Stigma: Breaking the Silence – Dealing with Stigma and Exclusion for People Living With HIV and Affected Populations Session Room 1

17:00-18:00 Sterilisation and Human Rights Think Tank WINZ

18:30-20:30 Advancing the Integration of HIV and Sexual and Reproductive Health. An Interactive Dialogue Session Room 6

Paving the Way to an AIDS-free Generation: The Role of Female Condoms in Comprehensive HIV Prevention Mini Room 5
Activists have long argued that a legal environment centred on defining and protecting human rights is a critical factor in producing an effective AIDS response and an essential element of ‘turning the tide’.

AIDS2010 saw this approach take centre stage with the Vienna Declaration. Since then, the United Nations Development Program (UNDP) and the Programme Coordinating Board of the Joint United Nations Programme on HIV/AIDS (UNAIDS) convened The Global Commission on HIV and the Law. The Commission spent one and half years investigating the intersections between HIV and various aspects of law, including through a number of regional dialogues, which offered grassroots organisations of sex workers, LGBTQ people, people living with HIV, and activists to give voice to their experiences with the intersections between law and life with HIV.

Yesterday, the Commission’s findings were presented in a special panel at AIDS2012. The panel not only summarised the broad findings of the report, but also pointed to the potential usefulness of the findings for changes in policy and the law, and raised the critical question; how can we build a movement for HIV, and activists to give voice to their experiences with the intersections between law and life with HIV.

...go beyond amassing evidence of the problem and toward mobilising constituencies for change...

Gender and HIV law

For women, the intersection between the law and HIV goes beyond the enforcement of unjust laws against people living with the virus. Shereen El Feki, of the Economist and a commissioner, reported in depth on the relationship between gender and HIV law, focusing mainly on North Africa and the Middle East, though the interconnections, she suggests, have significant overlap with many other countries. ‘Given that we were investigating issues relating to LGBTQ rights, the rights of injection drug users and sex workers’, she said, ‘one would have thought the rights of women as a group would be relatively uncontroversial’. Not so, according to el Feki.

Instead, she pointed out that in many countries a surface commitment to gender equality is belied by a lack of enforcement of both laws affording gender equality and basic criminal statuses (such as laws against rape and assault), when crimes are committed against women. Last, she notes that in many countries multiple legal frameworks, including customary or religious law, confound national policies on gender equality, depriving women of property rights, and protecting and entrenching practices, like early marriage, that make women vulnerable to HIV.

Women living with HIV also face violence at the hands of intimate partners and family; a quarter of women who reported disclosing their HIV status also reported being beaten as a result. In the care of medical staff, the report notes that women living with HIV face discrimination and stigma, as well as too-frequent abuse, such as forced testing, sterilisation and abortion, with ‘consent’ often illegally obtained for the former, while the women is in labour. El Feki is for prosecution of any health professionals engaged in such degrading and violent treatment immediately.

‘Key Populations’

Commissioners also noted that specific populations with significance with respect to the epidemic and response had particular relationships to the legal aspects of HIV. The report concluded that criminalisation and stigma against men who have sex with men (MSM), drug users, sex workers and transgender people have undermined public health efforts aimed at these populations in a number of countries, and violated individual’s human rights. Countries with punitive laws targeting these groups also tend to have higher rates of transmission and infection. In some cases, countries also tend to ‘underinvest’ in ineffective prevention strategies, such as condoms and lubricant, perhaps in large part out of moral concerns that such interventions could perpetuate the stigmatised behaviour. Stigma may also explain why to this day, two years after the Vienna Declaration, only 8% of funding for prevention research goes to investigate these key populations. Kenya emerged as an exemplar nation, where reform of stigmatising and criminalising laws has been undertaken to strengthen the AIDS response.

How can we build a movement?

This question was posed by the chair of the panel Mandeep Dhaliwal to the audience, many of whom have been engaged with just that question for years, if not decades. In...
Sterilisation and human rights think tank

On Wednesday at the WNZ advocates for the sexual and reproductive health and rights of women living with HIV will be launching a new issue paper assessing efforts to halt forced and coerced sterilisation of women living with HIV. The issue paper emerged from a Think Tank session organised on the eve of the 2011 International Conference on AIDS and STIs in Africa (ICASA) in Addis Ababa. This collaborative Think Tank mapped emerging trends at the intersection of sexual and reproductive health and rights and HIV, with a specific emphasis on the sexual and reproductive health and rights of women living with HIV. Our particular interest was to assess the state of the field in relation to violations of the rights of women living with HIV in sexual and reproductive healthcare settings. Given the current attention to and global consensus around the importance of integrating HIV and sexual and reproductive health, these violations pose a serious risk to the effectiveness of sexual and reproductive health and HIV integration efforts.

Among the general conclusions and recommendations of the issue paper is that we need more research and documentation of cases of forced and coerced sterilisation. This is particularly important for getting the attention of influential actors in the HIV and healthcare development sectors. In addition, we need urgently to educate women on their sexual and reproductive health and rights and at all levels, and empower them to challenge healthcare professionals. Furthermore, women living with HIV need to lead collective advocacy based on a common agenda. The session will discuss these actions part of the way forward, and define the next concrete steps to realise them.

Please come and join us in the Women’s Networking Zone on Wednesday, 25 July, 17:00-18h00.

Women’s Voices...
How can ARVs as prevention work for HIV negative women?

Jacqui Stevenson

A VAC, Sister Love and the Women’s HIV Research Collaborative, combined their sessions in the Women’s Networking Zone to host a joint dialogue session on the HIV clinical research agenda for women. The session created an opportunity for women to ask the urgent current questions on the clinical research agenda for women, and in particular on ARVs as prevention.

Recent developments in Pre-Exposure Prophylaxis (PrEP), are well-rehearsed at the AIDS 2012 conference. For women advocates, the priority now is to determine how women can benefit from advances in PrEP science.

Different women and different populations will be impacted by and benefit from ARVs as prevention in different ways. Context is everything, as always. In this session, the focus was on single HIV negative women, but all women will equally need and be entitled to the information they need to make their own choice about whether PrEP is right for them.

The key questions that we all need to ask are:

1. How will women identify and understand their own HIV risk in order to consider whether PrEP is relevant to them? How will clinicians and service providers do the same?
2. What information will women be provided on the potential side effects and protective effect of PrEP, in order to make an informed choice? How will they access this information?
3. How can PrEP be useful in contexts such as violence, and how will providers of related services be informed and supported to introduce PrEP to their discussions with women they support?
4. How do services find HIV negative women, in order to provide the information and support they need? In the absence of community services specific to negative women, or in absence of access to clinicians, how can PrEP reach the women who need it?
5. How affordable and accessible will PrEP be? How can it be rolled-out to ensure that no woman who wants it, is priced-out of getting it?

Implementing PrEP successfully to benefit single HIV negative women will depend on first answering these questions, and on recognising and responding to the fact that while questions remain the same across contexts, the answers will vary.

Jacqui is Head of Policy at the UK African Health Policy Network (AHPN).
In our opinion…

Time to de-silo our thinking…

Women living with and affected by HIV in diverse contexts face multiple barriers to fulfilling their sexual and reproductive health and rights. Women’s rights advocates, Jennifer Marshall (Choices, Memphis Center for Reproductive Health), Jeni Gati Mallet (Namibia Women’s Health Network), Maria De Bruyn (IPAS), Claudia Stoicescu (Harm Reduction International), and Luisa Orza (ATHENA) met in the WNZ on Monday to explore priority gaps, challenges and strategies to achieve women’s sexual and reproductive health and rights through innovative gender-based community approaches. Dustin James, Executive Director of the MidSouth AIDS Fund, moderated the conversation.

What do you believe will make the most meaningful impact on the sexual and reproductive health and rights of women living with HIV in the next 3 to 5 years?

We need funding agencies to get into a room and talk to one another, and work out ways for their grantees to collaborate, and provide capacity building and models of good practice to grantees to achieve that.

We need law reform. Women bear the brunt of laws that prohibit ownership or inheritance of land, laws that criminalise HIV transmission; laws that inhibit access to comprehensive sexuality education, and laws that prevent women from having safe legal abortions. Laws that are discriminatory against women in any way need to be changed – and changed laws implemented.

We need to legalise abortion.

We need to ensure access to integrated HIV and sexual and reproductive health services for women who use drugs. In settings where integration is not possible, we need strong referral systems between settings where integration is not possible, and laws that prevent women from having safe legal abortions. Laws that are discriminatory against women in any way need to be changed – and changed laws implemented.

We need investment in networks and organisations of women living with and affected by HIV, to have safe spaces in which to share and explore issues, and to organise to make sure that their lived realities are shaping policy and programmes.

We need policy makers to face the reality that young people are having sex, and we need access to family planning and youth-centred clinics to provide information and services to young women and adolescents on sexual and reproductive health.

What do you believe is currently the biggest challenge to the SRHR of women living with HIV?

Lack of information on sexual and reproductive health and rights – including for women living with HIV – that reaches both young girls and older women.

Laws and policies that criminalise drug use and possession. Many women do not access drug treatment or ARVs, because they fear that their children will be taken away from them because of their drug use. When we are talking about women who live with HIV, who use drugs, and who also do sex work, we are talking about so many layers of stigma that you cannot expect that just by providing a service women are going to use it.

Lack of awareness of existing services. For many, many years women living with HIV were told that they could not or should not have children. Overcoming messaging that has been around for so long – and building women’s belief that yes, there is somewhere in their community where you can receive those services; that yes, we will provide those services; that yes, we believe you have a right to a healthy pregnancy if that’s what you want…

Violence against women, especially against women living with HIV – and the structural set-up that makes us believe that this is basically ok – not only in the context of intimate relationships, but also in institutional services. Policies, services and relationships that ensure women’s safety are fundamental to realising sexual and reproductive health and rights.

The way policy makers think and the way we think about women – as mothers. Of course we need to keep mothers healthy, but women are not only mothers. They are much more. Why is it that women get access to ARVs when they are pregnant, but we are not using STI clinics, violence survivor services, abortion places and all the other places women go to get healthcare? Why are we not offering women as women access to ARVs through those channels?

How can SRHR and HIV advocates collaborate most effectively to fully realise the SRHR of women living with HIV?

By looking at the ways in which HIV and SRHR intersect and addressing them at their points of intersection.

By providing capacity and training to HIV providers … to reduce discrimination and build their confidence, so that they in turn can build the trust of their clients.

By calling for a WHO-endorsed comprehensive harm reduction package of interventions for women who use drugs that goes beyond provision of condoms, to provide international guidance on the needs of women who use drugs in relation to HIV.

By de-siloing funding … and by de-siloing our heads. Coming together at fora like this to learn about the different experiences and contexts in which people live, have sex, have children, and do whatever else they do … and to learn about the different strategies that are working.

By switching careers more often!

* Luisa Orza summarised the conversation.