In the International AIDS communities, men who have sex with men (MSM), transgender women and sex workers are much discussed as ‘high risk’ populations, but too often the most affected members of these communities are side-lined when it comes to strategy and decision-making in the AIDS response; a situation rendered starkly by the exclusion of sex workers and drug users from the DC Conference, due to restrictive US visa requirements.

The matter of incorporating the often complex experiences of these diverse constituencies at the centre of policy and programming goes beyond obvious questions of fairness. Speakers at yesterday’s plenary session Dynamics of the Epidemic in Context emphasised that the voices of people facing multiple stigmas and barriers to take control of their care are often the only source for vital information about how to effectively incorporate novel methods of prevention into the daily lives of those most at risk.

Despite the goodwill of delegates – the session was a sea of green ‘lady liberty’ headbands worn in support of excluded sex workers, while others sent postcards in solidarity with IDU’s – stigma cannot be defeated and exclusion ended by heart-warming rhetoric about empowerment. Dr Paul Semugoma of Uganda made his case clear saying ‘MSM exist in every country’, pointing out that there are still some countries who do not collect statistics about HIV in the MSM population. His own country, Uganda, is among those in the world with the most punitive legal and social environment for MSM – as a result, even doctors are often clueless or indifferent to MSM-specific health concerns and ignorant about even the most basic methods of prevention.

The patient who changed my life

Despite being a gay man, Dr. Semugoma was once just such a doctor. ‘I had been dealing with HIV among Ugandans, but never made the connection’ between MSM and HIV, he said, until being presented with a positive patient who was also gay and recently diagnosed. His question, ‘How do I protect my lovers’ led Semugoma down a path of self-education and activism that changed his approach to medicine and life.

Nevertheless, MSM in Uganda still face an uphill battle. The First LGBTI clinic was subject to ‘fierce criticism’ by government and civil society. In Senegal, government persecution of outreach workers made study of HIV in MSM nearly impossible, as participants were too intimidated to participate. Such stigma continues to shape the demographics of the epidemic, with prevalence among Black MSM across Africa and the Diaspora far exceeding those of comparable populations without multiple layers of exclusion. Even basic measures are still lacking. Semugoma passionately described the lack of condoms and lube in many African countries, incredulously noting that fully funding such interventions would cost $136 million – relatively cheap by standards of global health initiatives.

Cheryl Overs of Australia made the case for sex workers, similarly emphasising the need for clear
understanding of sex workers’ realities and calling for a back to basics approach, even while recognising that AIDS2012 represents a ‘new era’ of prevention comparable to the era of treatment, launched in 2000 in Durban. She argued that tension between biomedical and behavioural approaches to ending the epidemic are a red herring that fail to address the lived experience of sex workers themselves.

‘Sex workers understand that market forces determine what will happen’ and what approaches to prevention will work. She worries that microbicides and PrEP may increase client demands for condomless sex, noting that the internet already hosts discussion among clients hoping to be ‘freed from rubber’ in the near future by these advances. She also argued that such interventions may represent an increased financial burden on sex workers.

She noted the continuing criminalisation of sex work and HIV positive sex workers (in some states misdemeanour soliciting is increased to a felony if the sex worker in question is living with HIV), a situation that understandably discourages testing. She argued that what sex workers need most is a safe place to work and voice in the policies that impact them, summed up in the slogan ‘save us from saving’, while dramatically highlighting the loss of dignity and autonomy involved in many ‘anti-trafficking’ raids championed by both religious and political groups.

Overs argued that empowered sex workers themselves.

‘...stigma cannot be defeated and exclusion ended by heart-warming rhetoric about empowerment...'

...a voice in the policies that impact them...

worker communities can both protect themselves by collectively maintaining standards of condom use, and contribute to an effective research agenda on sex work.

One plate, one cup, one spoon

Debbie McMillan of DC Transgender Empowerment shared her own life story of multiple stigmas in a dramatic example of the complex interplay of disease and discrimination. She explained that her experience as an African American transgender woman and formerly incarcerated person, sex worker and drug user mean that she had lived a life ‘that practically guaranteed’ that she would contract HIV, though she believes she became infected through sexual violence that inevitably resulted from her imprisonment in a men’s prison. Saying ‘I represent the heart of the epidemic’, she also detailed her own mother’s history as an HIV positive sex worker and drug user; Debbie’s mother died while living with her own mother, in a home where she faced such intense stigma that she was only allowed to use her own separate ‘one plate, one cup and one spoon’. To Debbie, the discrimination she has faced not only from the criminal justice system, but also from healthcare providers recalled her mother’s experience. As a result, she emphasised the need for LGBTQI specific treatment for drug addiction and HIV.

The marginalisation laid out in these presentations at this plenary – implicitly the LGBTQI plenary of the conference – also highlighted the ongoing exclusion from the conversation of women who have sex with women and transgender, who – although not excluded by visa requirements – nevertheless went not only unheard, but unmentioned in the plenary. Like MSM, transgender women, sex workers and IDU’s, these populations face multiple stigmas and violence, and are the subject of very little research with respect in the International AIDS community. For these groups, the basic question posed to Dr Semugoma remains relevant: How can I protect my partner? and How can I protect myself?

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

An ‘uphill battle’...transgender in the U.S.

Kate Griffiths-Dingani

While the location of the AIDS2012 conference unfortunately excluded many transgender, sex workers and drug user activists from around the world, it has also had the unexpected benefit of highlighting community organisations representing marginalised groups in the U.S., many of which have been unable to fully participate in previous conferences.

Plenary speaker and staff member at Transgender Empowerment Debbie McMillan emphasised the importance of LGBTQI specific treatment options and organisations in her plenary address, noting in particular that the treatment programme which helped her ‘get sober’ after years of drug abuse and addition, Bridgetake, was closed for lack of funding. Unfortunately, this situation is not unique. In a country in which the rights of same sex couples to marry, and for LGBTQI people to live free of workplace and hiring discrimination remains subject to heated debate in the mainstream political sphere, organisations serving these communities face an ‘uphill battle’ in terms of adequate support, as well as ‘push back’ from the larger community.

As AIDS2012 got underway in D.C., a new service organisation, Casa Ruby, dedicated to providing a ‘safe haven’ for transgender Latinas living in the nation’s capital launched a campaign to offer free HIV testing to transgender people, as well as any other members of the community in need. This effort was met with death threats left on the organisation’s answering machine. Ruby Corado, founder of Casa Ruby, doesn’t see the incident as isolated, saying ‘I have been to dozens of funerals throughout this city and I have also been hundreds of times to the hospitals to aid people who have been victims of a violent crime or death for being who they are.’

Kate is an anthropologist and writer, who lives in Brooklyn, NY and frequently works in Durban, South Africa.
News from the Global Village…

The De Colores Trans Fashion Show Village came to the ‘village’ with colourful fashion and entertainment…

A benefit to all…?

‘The challenge in front of us is not treatment as prevention; it’s the healthcare system of the world that stinks!’ – Julio Montaner

In Tuesday’s discussion on ARVs for Treatment & Prevention: Human Rights Issues, Julio Montaner, described British Colombia’s (BC’s) dramatic reduction of HIV transmission and infection since the implementation of treatment as prevention. 55% of the infected population in BC now has undetectable viral loads. While this is an encouraging statistic, we must remember that 55% undetectable viral loads means that 45% of the people living with HIV can still transmit the disease.

In Wednesday’s session Maximizing Reproductive Possibilities and Choices for Women Living with HIV, John Ong’tech mentioned that if, for example, a woman required sperm washing, because it is one of the only possibilities for her to get pregnant safely, she has access to it…if she pays the equivalent to 200 USD. Statements like these were ubiquitously mentioned throughout many sessions at this conference. So the impression I get is, yes biomedical treatments for HIV are becoming more readily available, but the people who need the treatment cannot always access it.

In the same ARVs for Treatment & Prevention: Human Rights Issues session, Susan Timberlake from UNAIDS addressed this very nature of expanding bio-medical responses. She argued that if we do not invest resources into the reason people cannot access care and understanding the lack of adherence to HAART, then bio-medical advances will remain limited to the minority of people who can afford them. Without a change in healthcare systems, people with limited resources cannot access the services.

Treatment as prevention is not successful in Vancouver because Canada has money, as one might be inclined to think. What Canada has right is its healthcare system that helps the people, not just the top percent who can pay and access quality care. Montaner explains that the healthcare system in BC expanded to include the protection of basic human rights to create services that work for the people and for the betterment of the community.

So, in the midst of all the excitement about the potential of Treatment as Prevention, let’s not lose sight of ‘the challenges in front of us’ – the huge gap between people who need treatment and people who have access to treatment, inadequate healthcare systems, stigma barring access to services, and lack of investment in ensuring that all people who need access to ARVs (for treatment and for prevention) have access. Otherwise, biomedical advances will remain a ‘luxury’ for the few who can afford it…

Sierra is with the AIDS Legal Network, South Africa.
Women’s Realities...

A huge leap toward reproductive justice...

The Women’s Networking Zone played host to the launch of ground breaking clinical practice guidelines for pregnancy planning and HIV in Canada.

Shari Margolese, HIV positive community activist and co-author of the Canadian HIV Pregnancy Planning Guidelines was joined by Dr. Mona Louf, and Ms. Logan Kennedy of Women’s College Research Institute, Sandra Hon Chu of the Canadian HIV Legal Network, and Saskatchewan activist Ms. Krista Shore to engage international community and academic champions for the sexual and reproductive health and rights of people living with HIV in a critical dialogue on pregnancy planning in the context of HIV.

In Canada, improved life expectancy and quality of life for people living with HIV coupled with reduced vertical transmission has led numerous people living with HIV to consider pregnancy. The World Health Organization states that ‘all couples and individuals have the right to decide freely and responsibly the number and spacing of their children and to have access to the information, education and means to do so’.

However, due to HIV stigma, which frequently leads to the violation of human rights of people living with HIV, the discussion of healthy pregnancy and safe conception are not generally part of routine HIV care, and access to comprehensive preconception and conception resources and information is limited. The recognition of this gap between the reality of people living with HIV desiring, intending and having the reality of people living with HIV, the discussion of healthy pregnancy and safe conception are not generally part of routine HIV care...

...the discussion of healthy pregnancy and safe conception are not generally part of routine HIV care...

The guidelines were critically reviewed by Drs. Mark Yudin and Deborah Money both of whom are obstetrical/gynaecologists who work mostly with women living with HIV. Then all of the Canadian HIV Pregnancy Planning Development Team members reviewed the guidelines. The process of formulating recommendations for the NHPPG has involved lengthy deliberation of the available evidence and practical experience from Development Team members, including clinicians and people living with HIV. The team considered the health benefits, side effects and risks to prospective parents, as well as their unborn child. Additionally, cultural and practical considerations where taken into account when formulating recommendations, including the acceptability of assisted (non-natural) conception within various cultural groups, as well as access, availability and cost of assisted fertility services across Canada.

The guidelines were submitted for review to the Infectious Disease Committee and the Reproductive Endocrinology Infertility Committee of the Society of Obstetricians and Gynaecologists of Canada and published in the June 2012 Journal of Obstetrics and Gynaecology Canada. (www.sogc.ca)

Shari is a co-author of the Canadian HIV Pregnancy Guidelines.
Activists’ voices…
Re-igniting the spark!

One almost feels the sombre atmosphere as the panel of activists air their views on the issues they face in their various organisations.

The video from Alexei Kurmanaevskii of Russia gives the session attendees a chance to have a sneak peek in the life of a drug user. Addressing the white elephant in the room, which is the absence of fellow drug users, Alexei demands, ‘stop ignoring us. If you want to bring change, you can’t do it without us’, as the room breaks out in applause. ‘All we need is treatment, syringes, condoms; we do not want to be discriminated against’.

He was followed by Khartini Slamah from the Asia Pacific who addressed the session via a pre-recorded message. Khartini is on the Board of Directors of the Network for Sex workers. Due to the travel restrictions, she too, was unable to attend the AIDS conference. She demanded for the removal of travel restrictions and mobilised for a law reform. ‘We demand and advocate for affordable treatment medication so that it is affordable to those who need it’. She said sex work is work and thus demands equal rights. ‘We love what we are doing here and all of you in Washington will miss us’, she said as her message is met by chuckles and applause from the audience.

Gina Brown, from New Orleans, was another AIDS activist who started her presentation by highlighting other women activists who are not often talked about in comparison to their male counterparts. ‘I didn’t get into this fight for me, but for my daughter and others like her, who are affected but not infected’. Gina gave a passionate speech as she called out to others to come out and speak up. ‘I can still remember the day I was diagnosed. I didn’t know any women speaking out about HIV. I thought if I keep my mouth silent, how many more people will suffer? Stand up even if you don’t want to’. She called on mothers to train their daughters to also stand up and stand by their infected mother’s sides after they are gone. ‘We have to bring a face and a human touch to this. There is no space for discrimination in the next generation. Think about it’.

These were just some of the words from some of the activists. Their passion was clearly visible from their speeches and interaction with the audience. However, regardless of all the good work they are doing, most of it is affected by the absence of financing. One question they all had for each other was ‘where to from here’ and ‘tell me what you need from me, to help you’.

The session was closed off with a highly energetic chant from a fellow activist in the crowd chanting ‘if you discriminate, we fight back, we speak out, and we stand up. Roll up your sleeves and just do it!’ A true activist’s words…

Sirka is with ARASA.
‘It feels like we have been here before – another AIDS conference and another session ‘relegated’ to the Global Village, as the realities and needs of lesbian, bisexual and other women who have sex with women and are still excluded from the main conference programmes and the discussions in the ‘big’ rooms’. These were the sentiments expressed by Mabel Bianco opening the session on ‘building lesbian & WSW visibility in the HIV response’ on Thursday in the LGBTI Networking Zone.

The question ‘where are the lesbians’ in the response to HIV seems to remain a constant. At a similar session at AIDS2010 in Vienna (and before at AIDS2008 in Mexico), there was a common understanding that this ‘incredible invisibility’ of lesbian, bisexual and other women who have sex with women in the HIV response is not only related to homophobia, but also to a lack of data on specific prevention and treatment needs for lesbian and other women who have sex with women. And while we may have not come far in addressing homophobia since, there is now a growing body of evidence about the specific realities, risks and needs of lesbian, bisexual and other women who have sex with women. Yet, women who have sex with women are kept invisible in the HIV response. The question is ‘why’?

The data discussed at the session clearly shown how and why it is imperative for lesbian, bisexual and other women who have sex with women to be ‘visible’ and an integral part of the response to HIV. A study exploring HIV testing and HIV status among lesbian, bisexual and other women who have sex with women in Botswana, Namibia, South Africa and Zimbabwe revealed that 9.6% of the women participating and knowing of their HIV status (429) are living with HIV. Linda Bauman from OutRight, Namibia, who provided an overview of the results, also underscored that not sex with men per se, but non-consensual sex (with men and women) is a crucial risk factor for HIV exposure and transmission.

The risk of HIV exposure and transmission due to violence in its various forms, including social and institutional violence, as well as sexual violence and rape, was echoed with data presented by Gloria Carega from ILGA LAC Mexico, highlighting that lesbian, bisexual and other women who have sex with women are at risk of and exposed to violence and abuse, because they are women and because they are women who have sex with women. Recognising the high levels of violence and rape ‘targeting’ especially lesbian, bisexual and other women who have sex with women not only in Mexico, but in many parts of the world, it seems ironic, that although violence against women, including sexual violence and rape, has become more and more ‘visible’ in the response to HIV, the violence perpetrated against women who have sex with women continues to be ‘silenced’ and ‘invisible’. Again, the question is ‘why’?

The ‘obvious’ answer would be: homophobia, and societal ‘refusal to accept’ that women’s rights include a woman’s right to choose to be attracted to and have sex with another woman. But then, we have seen progress in recognising the role stigma (including stigma based on sexual orientation and gender identity) plays in the epidemic, and a growing inclusion of men who have sex with men in the response to HIV. Yet, the ‘invisibility’ of women who have sex with women remains. It is within this context that Maria Sjödin from the Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights raises the question as to the contributing role of the international rights activists’ community may play in upholding the ‘invisibility’ of lesbian, bisexual and other women who have sex with women. While women are now...
Andrea Gleaves, a domestic violence training and outreach specialist from the DC Coalition Against Domestic Violence, spoke in the Women’s Networking Zone about the interception of HIV and domestic violence. In 2010, Gleaves teamed up with the National Network to End Domestic Violence, as well as national, state and local level HIV organisations as the HIV/AIDS & Domestic Violence Project’s efforts to integrate the two sectors and improve services for women living with HIV, and survivors of domestic violence. HIV researchers, advocates, and policy makers know that gender-based violence both contribute and are a consequence of HIV. Gleaves’ focus on domestic violence in particular not only reinforced this knowledge, but drew upon unique connections between the two epidemics, as well as highlighted the significant strides being made on the cooperation between the two related sectors in American cities and around the world.

During training, the HIV counsellors and domestic violence service providers attended workshops to enhance their knowledge on the ‘other sector’ and to create a common foundation of knowledge across the two sectors. Gleaves points out that it is important for women who work with domestic violence survivors to be comfortable and knowledgeable when confronted with a situation involving HIV and vice versa, saying that ‘it is impossible to talk about domestic violence without talking about HIV.’

Quickly, commonalities between domestic violence and HIV were distinguished and addressed. Perhaps the most notable similarity between the two were the typical domestic violence ‘Power and Control Wheel’ where the ‘spokes’ are the gateways or tactics to domestic violence that include: economic abuse, male privilege, sexual abuse, threats, blame, intimidation, and isolation. While the stigma associated with a domestic violence survivor and someone living with HIV may be different, there are many shared experiences between the two, all of which are unique to women. Not surprisingly, many of the domestic violence abusive tactics could be seen on the women living with HIV wheel.

A positive consequence of these collaborations and cross training is that the DC Coalition Against Domestic Violence, as well as other shelters and domestic violence offices around the country, have visuals of ARVs; so when a woman who experienced domestic violence comes to them, they can identify the type of pill and the medication she needs timely. This is but one example of the potential changes that can be made when sectors partner-up and systematically address the specific needs of women living with HIV and women survivors of domestic violence.

Local Voices: Integrating sectors…

Sierra Mead

Andrea Gleaves, a domestic violence training and outreach specialist from the DC Coalition Against Domestic Violence, spoke in the Women’s Networking Zone about the interception of HIV and domestic violence. In 2010, Gleaves teamed up with the National Network to End Domestic Violence, as well as national, state and local level HIV organisations as the HIV/AIDS & Domestic Violence Project’s efforts to integrate the two sectors and improve services for women living with HIV, and survivors of domestic violence. HIV researchers, advocates, and policy makers know that gender-based violence both contribute and are a consequence of HIV. Gleaves’ focus on domestic violence in particular not only reinforced this knowledge, but drew upon unique connections between the two epidemics, as well as highlighted the significant strides being made on the cooperation between the two related sectors in American cities and around the world.

During training, the HIV counsellors and domestic violence service providers attended workshops to enhance their knowledge on the ‘other sector’ and to create a common foundation of knowledge across the two sectors. Gleaves points out that it is important for women who work with domestic violence survivors to be comfortable and knowledgeable when confronted with a situation involving HIV and vice versa, saying that ‘it is impossible to talk about domestic violence without talking about HIV.’

Sierra is with the AIDS Legal Network, South Africa.

Johanna is with the AIDS Legal Network, South Africa.

It seems ironic that while we are talking about turning the tide for women and girls and turning the tide to end violence against women, the voices and needs of women who have sex with women who remain ‘silenced’ and ‘invisibilised’. And as for looking forward, Melbourne here we come; and this time, the realities, risks and needs of lesbian, bisexual and other women who have sex with women will be part of the main conference programme and the discussions in the ‘big rooms’. Without the visibility of women who have sex with women, turning the tide … and ending AIDS will remain but a dream…

... non-consensual sex (with men and women) is a crucial risk factor for HIV exposure and transmission…
The centrality and value of involving women living with HIV and other key affected women in all aspects of the HIV response has long been recognised.

The principle of engagement has been codified in various political commitments going back to the coining of the principle of the Greater Involvement of People Living with HIV (GIPA) in the 1994 Paris Declaration, and reiterated in the 2001 UNGASS Declaration of Commitment, and the 2006 and 2011 Political Declarations. Nevertheless, women living with HIV and other key affected women, continue to face significant challenges and barriers to accessing political spaces for meaningful participation in, and to realising their leadership. Moreover, these challenges remain largely unchanged over the last decade.

Women-and HIV activists have been talking about the same things for so long now, that GIPA (or better MIWA: the meaningful involvement of women living with HIV) fatigue must be setting in. Yet, taking our eye off the ball, and the back-slide occurs in a flash. Take AIDS2012, where the planning failed to include a woman living with HIV among plenary speakers. The Make Women Count movement was quick to respond and push back, resulting in Linda Scruggs’ extraordinary and powerful presentation on Wednesday. But one thing is clear: people would much rather see their seats, with seats, are truly representative of those without.

Among others, issues that continue to stand in the way of HIV-positive women’s meaningful involvement and leadership include: literacy – including rights literacy, – language barriers, and lack of access to information; insecure livelihoods; stigma, discrimination and violence against women living with HIV at household, community, and institutional levels; voluntarism, the burden of care, burnout, and the lack of recognition for the contribution that grassroots women have made to the HIV response; largely through the investment of their own resources; lack of specific skills to engage with policy, budgeting, monitoring and evaluation and accountability frameworks from a human rights and gender perspective; lack of funding to organise and engage, and patriarchal gender norms which result in a heavy burden of domestic and reproductive work, and underrate the potential and value of women’s political representation and leadership.

Securing a (lasting) place at the table for women living with HIV is step one. Beyond this, governments and development partners must:

1. Provide a range of accessible funding options, including core funding and seed grants for women’s organisations and networks
2. Develop mechanisms, tools, and processes to ensure the meaningful participation of women living with HIV in the planning and budgeting processes of national AIDS strategies, operational plans, and accountability frameworks, as well as in monitoring expenditures and results
3. Invest in training and capacity strengthening for women’s organisations and leadership beyond the delivery of care and support services, to enhance engagement in policy processes; and, promote social protection mechanisms to meet material needs as well as empower women through skills development
4. Ensure women’s access to information: invest in legal literacy and rights awareness among women, especially women living with HIV, including through translation of relevant legal and policy resources into local languages
5. Strengthen capacity among implementers and policy makers to effectively engage in two-way learning and dialogue women living with and affected by HIV
6. Invest in women’s HIV prevention, care and support programmes
7. Bridge the disconnect between national and local decision-making processes to ensure women’s voices are carried through from local to national levels
8. Address cultural barriers, patriarchy and gender norms that prohibit women’s engagement, including through
   a. addressing the gender division of labour, so as to create time and space in women’s domestic labour, for women’s effective engagement in the public sphere
   b. engaging men and boys to break-down gender norms/cycles, and promote gender equality, and
   c. sensitising men to the importance of women’s political participation
9. Work with women’s organisations and networks to define benchmarks and articulate indicators of success for women’s meaningful participation
10. Transform signatures into action: implement existing normative frameworks that uphold women’s rights, and promote women’s political representation

Footnote:
1. These standards for meaningful participation are drawn from a satellite session at AIDS2012 on ‘Women Leading, Organizing and Inspiring Change in the AIDS Response’ hosted by UN Women in partnership with UNAIDS, ATHENA Network, Huairou Commission, and the Canadian International Development Agency.

Luisa Orza

Supported by the Oxfam HIV and AIDS Programme (South Africa) and the South Africa Development Fund

Editors: Johanna Kehler, tyler.crone@gmail.com, jkehler@icon.co.za
Photography: Johanna Kehler, jkehler@icon.co.za
DTP Design: Melissa Smith, melissas1@telkomsa.net
Printing: B&B Duplicators INC, bandbduplicators.com

www.aln.org.za
www.athenanetwork.org