

# Mujeres Adelante

Newsletter on women's rights and HIV • IAS 2011 • Rome

## In Focus...

Zena Stein and Ida Susser

# Science advances become *real* advances for women...<sup>1</sup>

This paper has two parts: first we describe the exciting advances in the science of HIV prevention achieved over the past three years; second, we turn to face the future, and somewhat surprisingly, we find ourselves charting a new and different direction.

### Advances

Precisely one year ago at Vienna we stood and cheered long and loud the announcement that Tenofovir 1% gel, not exactly a microbicide but an antiretroviral treatment, could also act as a preventive against HIV, if applied at the right dose and at the right time in the right place. In comparison to women using a placebo gel, the use of Tenofovir 1% gel halved the number of infections among the women who used it correctly. And still, one year later, we applaud this outstanding potential. However we ask ourselves now: Why only potential? Why is this significant addition to HIV prevention for women not yet available and accessible? We will consider this in the second part of this paper.

The next important achievement this year is the confirmation that

treatment reduces transmission of HIV. It was shown recently, in an international trial, that if an infected woman or man is placed on antiretroviral treatment and is adherent to it, her or his partner is virtually completely protected from infection. Although this is



not a brand new finding, we hail the widespread recognition of its significance. For a woman, this finding allows her to bear children with an infected man, if she so chooses, because she will not be infected with insemination. Similarly, should she herself be infected and undergoing treatment, she may also have sex with her partner safely and conceive, should she so wish. She will also be able to protect her foetus and infant.

Further, we now know that if a woman is tested at a prenatal examination, and whatever the level

of her CD4 count, she is placed immediately, on a full and lifelong treatment regime of antiretrovirals, not only will her health remain protected, but so will that of the infant. She can safely breast feed the child, at first exclusively, and then as long as she chooses, because she will remain with an undetectable viral load.

Both women who are uninfected and those who are infected have received great news. In addition, we hope that women can reduce their risk of infection if men themselves acquire some protection. Controlled trials of medical male circumcision show that the procedure could raise their protection against HIV for men by perhaps more than one half. If men follow this practice, before they become infected, this could reduce women's rates of infection in the long run.

New approaches based on statistical models also give some cause for optimism. The theory dubbed 'test and treat' proposes that if a far greater proportion of people in a community volunteer for HIV testing, and if those who are discovered to be positive are actively counselled, and assigned to antiretroviral treatment earlier in the disease than at present, then the number of transmitters in the community would be reduced. The

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idea is to coordinate treatment with prevention and encourage optimal approaches to each.

Three other trials have also made the news. One is the IPREX trial, which showed that prevention of infection in men who have sex with men was possible, if men take a pill, which is also an antiretroviral. The degree of protection (about half among users) was similar to that of the Tenofovir gel among women. If men take this pill, bisexual men, at least, will have fewer infections. Women may eventually benefit from this finding, because anything that reduces infections among men should eventually reduce the risk of infection among women.

Less happily, a similar trial of the same pill among women (the FEM-PrEPStudy) was stopped before completion because of '*futility*' (the statistical term to show it was unlikely to work). This apparent lack of protection is compatible with biological awareness that the anus, but not the vagina, would accumulate in the drug with oral use.

One other important trial bridges the gap from community to action. NIMH Project Accept, working in 32 communities in Africa and Asia showed that community-based measures facilitating voluntary HIV testing improved the proportion of volunteers who underwent testing, compared to clinic-based testing.

Future '*combination*' studies are planned, including testing, access to care treatment, counselling and prevention.

### Questions and future strategies for women

Despite these advances, HIV is not yet controlled and/or conquered. Hence the question arises, are we to wait, passively, for another decade of randomised controlled trials and '*evidence-based*' findings? For how long will the licensing procedures, the manufacturing, packaging and distribution problems hold up access? Are there other ways

to put into effect more of what we know?

One delaying action, against which we continue to argue, as we have over the past 12 months<sup>2</sup>, is the failure to move from what we do know to what we do not know. This is best exemplified in connection with Tenofovir gel. Thus, we do know that perhaps half of the women who were placed on the gel were protected, but not why this is only half, or if the explanation is biologic or behavioural? For instance, is it the nature of the virus or the immunological response of the woman to the virus in the presence of the drug that determines protection? Or, is it the distribution of the drug in the vagina?

Alternatively, is the determination of success behavioural: default or variation in the women's usage of the gel or a decline in their use over time? All these and other questions have been raised.

One approach, supported by many of the best-known and most-experienced workers in the field of microbicide development, is to repeat the trials. Certainly it has been argued that regulating bodies will demand these further trials, before the gel can be licensed. However, this is a political rather than a scientific justification. Should we allow political concerns to override scientific and certainly ethical issues? The view that regulating bodies require further randomised control trials (RCTs), if it is true, has not yet, to our knowledge, been actively and openly challenged, despite the history and successes of activism in the HIV field. If, for instance, safety against adverse events needs further studies, then, as we urged elsewhere, post-marketing observations involving large numbers, should be enforced. For really rare events, it is the incidence of these events, rather than the relative risk based on trials, that will be informative.

In fact, many researchers hold

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that, at this point, some randomised control trials are both non-informative and unethical. Answers to some of the most pressing questions as listed above will accrue from studies of women using the drug in one way or another – such as less or more drug, different times, or behavioural changes. RCTs, which require women assigned to placebos, are very limited in their flexibility and are not helpful in answering the next set of questions necessary for women to benefit most from current findings.

Is this good science? Is it worthwhile expenditure? Is it fair on the women concerned? Are we delaying or forwarding implementation? Are we, in pursuit of so-called evidence base, distorting the logic of the questions to be answered?

We ask these questions in the spirit of openness, respect and co-operation that has characterised the microbicide movement for nearly two decades. There may be good reasons for these steps that we are here questioning, but it seems appropriate to, raise these questions.

We, and others, strongly recommend further research, but urge that it conform to scientific and ethical standards. We should not be misled by political issues. We cannot replace scientific questions with a simple equation of '*evidence-based*' with RCTs. Nor are RCTs always the Gold Standard as the best choice of method. This may depend upon the particular question, which may be local, regional or universal.

We are emphasising, here, local initiatives which facilitate local experiment and innovations. For instance, given that: Tenofovir gel will apparently protect only about half of conscientious users, and we do not yet know which half: not all infected male partners will know their status and be on appropriate treatment; and very young women are at an elevated risk, what should we do to repair these gaps in the field?

We here advocate local community organisation perhaps led by clinics and providers, perhaps by women activists, perhaps mothers and daughters, perhaps clubs. Their role is to spread knowledge and experience not only of what we have summarised above, but also of what women might use besides.

We also propose that other barriers are likely to still be important and likely to continue that way, perhaps until and even after we have a vaccine. For example condoms: if all women used female condoms or if all men always used condoms sexual transmission would disappear. Can the female or the woman's condom be more widely used? Can negotiation help, with male condoms? What about alternative barriers, such as the cervical cap, likely to protect against chlamydia and gonorrhoea, HPV? Which methods, in which communities, and, after what instruction and encouragement, would women learn and be enabled to use these methods?

Would clinics acquire the equipment, the training tools, the encouragement to evaluate preferences, regularity of use, perhaps effects of female condoms, male condoms and other barrier methods? Implementation science has begun to focus on managers and providers. An informed army

of providers, skilled and trained local community workers is needed. Could a mobile group of trainers travel and gain and transfer experience? Would this be a better way to spend funds than on future trials of known 'facts' and the repetition of 'evidence base' that is now the pattern for funders, national and private.

Of course, these approaches are not mutually exclusive, but it always seems easier nowadays to acquire funding for larger, rather than for smaller endeavours. Although funders pay lip service to action and advocacy they rarely fund local examples of innovative practice, imaginative and collective endeavours. Further technical advances like a widely effective vaccine, may be decades away. In the meantime, we have to work with people, with what they believe and know and how they can use these concepts and facts.

Outcomes that may be more durable in the long-term, like overcoming stigma, might be developed in schools and in women's clubs. Knowledge and understanding at the people level may be where HIV can be most effectively prevented at present.

As this summary has outlined, treatment and prevention are intertwined and good treatment can also be good prevention. However,

...the failure to move from what we do know to what we do not know...

...at this point, some randomised control trials are both non-informative and unethical...

we need to work on the community side for any of our scientific findings to actually reduce infection and to help people living with AIDS to live full and healthy lives, with the choice to bear and rear healthy children.

1. For more information see 'Ethics, Equity and Equipoise: Are further placebo-controlled trials of antiretrovirals to prevent sexual transmission needed and justifiable?', Kuhn, L., Stein, Z. & Susser, I. [accepted for publication in the *Lancet* 2011, to be released 16 July]
2. Stein, S. & Susser, I. 2010. 'Microbicide Success: New opportunities for women'. Published with responses from specialists in the field. In: Special Issue of *ALQ/Mujeres Adelante*, October 2010, pp.38-56 [www.aln.org.za]; Microbicide Success: Feminism is Essential to Good Science. Athena Network & AIDS Legal Network [www.athenanetwork.org]

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### In Women's Words:

Sex workers experience debilitating stigma and discrimination that erode their ability to protect their health and well-being. As a result of law and social practice, sex workers face difficulties accessing healthcare, housing, and supplementary employment opportunities. They risk verbal, physical, and sexual abuse, arbitrary arrests, and harassment. Stigma decreases their ability to seek protection from the courts or the police when they suffer from violence and discrimination. HIV/AIDS programmes should teach sex workers about their legal and human rights towards a renewed sense of dignity which will compel them to collectively demand justice and relief from discriminatory practices. Programmes should promote acceptance of sex workers and people living with HIV/AIDS in media campaigns and healthcare services. They should make efforts to propose an alternative to the morality framework through which sex work is generally viewed. Furthermore, programmes should participate in debates regarding how laws against sex work obstruct HIV prevention efforts.

[India]

Silvia Petretti

# Watch out Europe! Here SHE Comes... The SHE Programme

**I am extremely excited that the IAS HIV Pathogenesis Conference in Rome in July 2011 will provide the context in which the SHE Programme will be launched. This is because Rome is not only the city where I was born, but is also where I was diagnosed HIV positive over 14 years ago.**

At the time of my diagnosis peer support for women with HIV was not available in Rome, and I had to go through the most difficult times in my life without access to any psycho-social support.

Things changed for me when I moved to London and I started accessing peer support groups at Positively Women, and then started working for the organisation, which is now known as Positively UK. I know, because of the hundreds of women I have supported for more than 10 years, that peer support enables women with HIV to regain their self-esteem and confidence to be in control of their health and ultimately of their lives. I really hope that one day no woman



who gets diagnosed with HIV will have to go through the terrible fear and isolation that I experienced when I received my diagnosis, and I believe that the SHE resources can play an important role in creating such a world.

**...many women are left with an unaddressed gap between diagnosis and effective, informed healthcare...**

Sadly, in Europe, the number of women living with HIV is on the rise.<sup>1</sup> Despite improved long-term treatment and prognosis, HIV remains complex, imposing unique challenges for women. Couple women's social vulnerability to HIV with a lack of HIV programmes and resources that address our specific needs, and many women are left with an unaddressed gap between diagnosis and effective, informed healthcare.<sup>2</sup>

The SHE (Strong, HIV positive, Empowered Women) programme is designed to address this disparity and bridge the knowledge gap between physicians and women living with HIV by providing resources, including a toolkit to be used by women living with HIV in a peer support setting, as well as a website<sup>3</sup> ([www.shetoshe.com](http://www.shetoshe.com)). Women across Europe will be able to access the site – on their own time, at no cost, and with full assurance of personal privacy. These resources were developed by people living with HIV in collaboration with healthcare professionals and offer help to overcome the daily obstacles women with HIV may face.

The SHE programme is based on a peer-support model. Obviously, I have personally experienced huge gains by accessing this kind of support; moreover, research shows information provided by peers is seen as particularly credible and influential. Peer educators also provide inspiring role models to women living with HIV, while personally benefiting from the process.<sup>4</sup> Benefits for all participants include

enhanced self-esteem, increased sense of empowerment, and being better informed, resulting in greater skills and self-confidence during clinician consultations and therapy.

To support this model, the SHE advisory board, which I co-chair with Prof. Jane Anderson, will unveil a practical, information-based toolkit for use by peer-support volunteers or workers in clinical settings. The authors of the toolkit, all personally impacted by HIV, specifically developed

**...bridge the knowledge gap between physicians and women living with HIV by providing resources...**

this resource to be useful in real-life situations and easy-to-understand, truly addressing the unmet needs of women living with HIV. The toolkit covers topics

such as diagnosis, disclosure, sex and relationships, living well with HIV, getting the most out of treatment, and addressing human rights issues.

It also contains a section for health care providers highlighting the value of peer support and the SHE programme.<sup>5</sup>

Running parallel to the SHE patient education programme is a scientific advisory board of European healthcare professionals committed to developing best practices regarding management and treatment for women living with HIV.

Furthermore, the SHE programme aims to engage policy makers to consider the special issues confronting women living with HIV, thereby increasing awareness, understanding and solidarity throughout Europe.

The SHE programme will be unveiled at the IAS 2011. During the SHE launch meeting, SHE authors, SHE programme co-chairs, Prof. Jane Anderson and

myself, advisory board members and ambassadors will conduct an interactive session to train participants on peer support best practices and how to incorporate SHE tools and resources.

1. WHO. December 2009. 'Annual rate of newly diagnosed HIV infections in Europe more than doubled'. [www.euro.who.int/en/what-we-publish/information-for-the-media/sections/press-releases/2009/12/annual-rate-of-newly-diagnosed-hiv-infections-in-europe-more-than-doubled]
2. UNAIDS, UNFPA, UNIFEM. 2004. Women and HIV/AIDS: Confronting the Crisis. [www.genderandaids.org/downloads/conference/308\_filename\_women\_aids1.pdf]; WHO. Gender inequalities and HIV. [www.who.int/gender/hiv\_aids/en/]
3. This website address is to be confirmed.
4. van Uden-Kraan et al. 2008. 'Empowering processes and outcomes of participation in online support groups'. Quality Health Resources, 18; pp405-417.
5. The UK version of the toolkit will be available at IAS 2011. Localised adaptations of this toolkit will follow.

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### In Women's Words:

**P**romotion of the sexual and reproductive rights of women living with HIV is urgent, because the State does not have a clear position. Women living with HIV do not have clear guidance about their rights, nor do they get full access to contraceptive methods. They are guided to not have children and there is not a comprehensive approach. [Latin America]

### In Women's Words:

**H**IV testing is not offered broadly in the maternal and child health care environment, so most women discover their HIV diagnosis when they or their partners become ill with AIDS, or when a child dies from AIDS. [Mexico]

Luisa Orza

## In Women's Words: Women as a category of intervention...?

During February to April 2011, the ATHENA Network and the Global Coalition on Women and AIDS conducted a Virtual Consultation to provide a platform for women's voices in the lead-up to the High Level Meeting on HIV and AIDS in June, 2011.<sup>1</sup>

Translated into nine languages, the virtual consultation enabled 800 women from 95 countries to voice their priorities for the future of the HIV response, and to review progress made against



commitments of key relevance to women and girls enshrined in the 2001 UNGASS Declaration on HIV and AIDS and the 2006 Political Commitment.

Through a team of regional focal points and technical

experts, the consultation reached out to women around the world, including women living with HIV, young women, sex workers, women who inject drugs, grassroots women, and other key affected women, such as women in prison or detention centres, indigenous and rural women, transgender women, and lesbian, bisexual, and other women who have sex with women.

### Women's priorities

Globally, the top priority for positive change towards achieving

health and rights for women and girls living with and affected by HIV, as identified by the survey respondents was:

**Inclusive and holistic prevention, treatment, care, and support for women in *all* of their diversity:** Increasing access to and uptake of prevention and treatment services (including nutrition) for women and girls *outside* of the maternal and child health setting

Key components of this ask, distilled from the priorities enumerated by survey respondents, include the following:

- Health services must be accessible, gender-sensitive, non-discriminatory, and uphold confidentiality; and be available for *all* women, regardless of age, HIV status, sexual orientation, or socio-economic status.
- Promote the inclusion of women and girls in *all* their diversity, such as those living in rural and hard-to-reach areas, young women, women living with HIV, women with disabilities, women in conflict areas, transgender women, women who have sex with women, women involved in sex work, refugees, women who use drugs, and indigenous women.
- Promote youth participation, and youth-friendly SRH/HIV services, in particular ensuring access to non-judgmental services for young people.
- HIV prevention and access to HIV testing must be available for *all* women, not only when they are pregnant, but also throughout their life cycle.
- Expand gender-sensitive, non-discriminatory, and supportive harm reduction and needle exchange services.
- Promote comprehensive and integrated provision of HIV and sexual and reproductive health services to

allow *all* women and girls, including those living with HIV and minors, to enjoy a safe and satisfying sex life, free from violence and discrimination, and to decide about the number and spacing of their children.

*Most of the HIV prevention programmes are addressed to reduce risk factors that increase the possibility of getting HIV (number of sexual partners, use of condoms, etc). Almost no HIV prevention or care programme is directed to reduce the vulnerability conditions in which women acquire HIV (poverty, violence, gender roles, lack of education, lack of leadership, etc). [Latin America]*

*Positive women are not offered a comprehensive range of family planning options, and are vulnerable to unwanted pregnancy. [West and Central Africa]*

In addition to asking women for their top priority issues, the consultation utilised 10 mutually reinforcing building blocks to review progress and take stock of issues affecting us in the context of HIV, constituting core elements of the HIV response essential to achieving health and rights for women and girls. Moreover, it is clear from the analysis that particular attention needs to be paid to women and girls living with HIV, and other key affected women who frequently experience further marginalisation as a result of being criminalised, stigmatised, or invisibilised at community, institutional or state levels.

### **Positive changes**

*It is important to note positive changes that have occurred over the last 10 years, particularly in relation to access to health services, including SRH services to women living with HIV. Increased access to ART has clearly contributed to an increase in the type of services available to women living with HIV, particularly cervical cancer screening and family planning methods available. [Asia and the Pacific]*

The virtual consultation recognised that great strides have been made over the past decade in responding to the HIV pandemic, both in terms of bio-medical advances, and in terms of acknowledgement of the need for evidence-based rights-driven responses. These include recognising the importance of women's and girls' sexual and reproductive health and rights, including for those of us living with HIV. Prevention technologies, such as the female condom, post-exposure-prophylaxis (PEP), microbicides, pre-exposure prophylaxis (PREP), and treatment as prevention, are critical tools towards advancing a sexual and reproductive

### **10 Building Blocks of the HIV Response for Women, Girls, and Gender Equality**

1. Meaningful involvement of women and girls living with and affected by HIV
2. Solidarity with women and girls living with and affected by HIV
3. Safety for all women and girls
4. Acceleration of gender equality through the HIV response
5. Integrated services, especially sexual and reproductive health and HIV
6. Sexual and reproductive health and rights of women living with HIV to receive comprehensive perinatal care and to have children free of HIV
7. Women-centered HIV prevention technologies
8. Comprehensive sexuality education
9. Investment in care and caregivers
10. An HIV response that works for women and girls in *all* of our diversity

rights agenda within the context of the HIV response. Similarly, the huge scale-up of antiretroviral treatment, the WHO four-pronged approach to prevention of vertical transmission, and expanded understanding of a comprehensive and holistic care package for people living with HIV has emphatically improved the life chances and quality of life of many people living with HIV around the world.

At the same time, however, responses to the consultation reinforced the need for recognition that bio-medical advances are not made within a vacuum. Our daily realities, and the social context in which we live, intersect with the bio-medical HIV response, and our ability to access and effectively utilise prevention, treatment and care technologies. An effective HIV response must look beyond a bio-medical response to address structural inequalities through the promotion of rights, dignity and meaningful involvement of women in *all* our diversity.

Prevention, treatment and care approaches need to take into account the realities of our lives, including our ability to access information and services; negotiate the effective and consistent use of prevention technologies; and retain our human rights – including our sexual and reproductive rights – and dignity.

*Prevention technologies are useless if women do not have the confidence and skills to negotiate them with their partners. The lack of funding for women's groups means that women are often not well-informed on those technologies. Women in prison, women who have sex with women, and drug users are further excluded.* [UK]

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Thirty years into the HIV and AIDS pandemic, HIV-related stigma remains a major barrier to achieving universal access goals. This often intersects with other forms of stigma and discrimination – in some cases reinforced or upheld by punitive laws

and criminalisation – based on our gender or gender identity, age, race or ethnicity, sexual orientation, drug use, sex work, marital status, (dis)ability, fertility, immigration, refugee or asylum status, actual or previous detention, literacy, socio-economic background, and domicile.

*The denial of the existence of women who use injection drugs, lesbian, bisexual women, women who sleep with other women and transgender women means these groups' issues are never looked into.* [Zimbabwe]

*Care and prevention services are available through a few high profile organisations in Jamaica but funding limits their access to major towns, requiring perhaps a high level of initiative towards self-care outside target populations.* [Jamaica]

*Women from rural areas are doubly excluded.* [Honduras]

**...a result of being criminalised, stigmatised, or invisibilised at community, institutional or state levels...**

HIV-related stigma and discrimination within the health services – in particular with regard to the sexual and reproductive health and rights of women living with HIV – continues to be a common experience. Mandatory HIV testing for pregnant women; lack of access to a full range of contraceptive information or choice for women living with HIV; partial or inaccurate information about conception, pregnancy and childbirth for women living with HIV; involuntary disclosure as a result of the indiscretion of health professionals; and coerced or forced sterilisation or abortion all constitute violations of women's sexual and reproductive health rights.

*Women who attend antenatal clinics are coerced to test by being told it is a government requirement, and so they*

*must. My sister told me she was told the 'president of the republic' demands all women attending antenatal clinic must be tested. Women, who are poor, have not gone to school or don't know their rights, never ask questions but succumb. While they sign consent, they have no other choices.* [Kenya]

*Women with HIV who want to have children or to use any family planning method other than sterilisation are strongly questioned, stigmatised and discriminated.* [Dominican Republic]

### Interface between violence and HIV

Over the last three decades, there has been a growing awareness, understanding and outrage of the gender dimensions of the HIV pandemic. And while resources are frequently still deflected away from women, the HIV response has also created opportunities for those on the margins to take the centre stage, and a dynamic moment in which to advance a gender agenda.

*Challenging social norms, standing up to the powerful elite in the district – police, village panchayat leaders, politicians and upper-caste village leaders has involved developing a dynamic social discourse. At the state and national level some success has been achieved in the engagement with government and non-government actors. Working with networks of sex workers, women's groups, HIV/AIDS activists and queer activists within the country and outside has resulted in concrete gains.*

*This should be encouraged.* [India]

Sadly, however, such opportunities have remained isolated, piecemeal or lacking in sustained investment. In particular, greater attention is needed

around the interface between violence against women and HIV, both as a cause and consequence of transmission. Violence against women and girls (including against those of us living with HIV) acts as a powerful barrier to our accessing and utilising HIV prevention, treatment and care services in complex ways, often encompassing diverse forms of violence, which play out in intimate, institutional and structural spaces.

*Women can access free condoms in care centres and testing sites, but cannot request, let alone insist, on condom use or other form of protection. If they refuse to have sex or demand that a condom be used, they may risk suffering violence because they are suspected of being unfaithful.* [Middle East and North Africa]

This calls for a new conceptualisation of the phenomenon of violence against women living with HIV, occurring at the nexus of multiple structural determinants, including (but not limited to) gender inequality and HIV-related stigma and discrimination. One of the ways in which violence against women living with HIV can be differentiated from violence against women is in the impact it has on a positive woman's ability to access and effectively utilise HIV-related prevention, treatment, care and support services, programmes, medication and technologies.

*A woman living with HIV who is subjected to violence of any kind is potentially a woman who abandons her treatment and dies.* [Argentina]

In countries where sex work is not legally recognised, the rights of women who engage in sex work are automatically

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**...address structural inequalities through the promotion of rights, dignity and meaningful involvement of women in all our diversity...**

eroded, and punitive laws and criminalisation of sex work support broad-based stigma and discrimination, leaving sex workers vulnerable to multiple abuses of rights. Similarly, women who use drugs (in contexts of punitive drug policies) and women in prison or facing deportation do not have access to the same mechanisms of rights protection as other women. Violence against women continues to be underpinned by the belief – frequently internalised – that those against whom violence is perpetrated must have done something to deserve it.

Violence against women – including violence against women living with HIV – needs to be recognised as a manifestation of unequal gender relations, frequently intersecting with other structural inequalities of power, and not as a series of isolated, if coincidental, individual experiences.

### Service linkages

In recent years, actors in the AIDS response, from community groups to international policy developers, have increasingly recognised the benefits of integrating service integration, in terms of providing efficient services, reducing duplication of efforts, and ensuring that key affected individuals and populations do not ‘*slip through the net*’ by focusing on one set of health needs while overlooking another. Often community driven in the first instance, service linkages recognise that people have multiple identities and related health concerns, and promote a holistic, rights-driven approach to healthcare at all points along the HIV prevention, treatment, care and support continuum. However, while many examples of good practice

exist, service linkages – particularly those which aim to address the sexual and reproductive health and rights of marginalised and key affected women – continue to remain the exception rather than the norm.

*Punitive models remain the norm addressing drug use and sex work, and they don't help prevent HIV, rather the contrary. Sex work related services are not integrated at all and drug use related services are rarely integrated. Testing is available, but low education levels mean that confidentiality is not widely understood and the promotion of criminalisation of HIV transmission makes it dangerous to know one's status if one is sexually active and HIV+. This is a deterrent to testing and care and treatment. [USA]*

While prevention of vertical HIV transmission programmes have frequently been held up as a standard of success in the HIV response, the focus of such programmes often still focuses on the health outcomes of the baby, rather than also promoting the health, rights and dignity of mothers living with HIV. Even where vertical transmission services are excellent for women who test HIV positive during pregnancy, women do not always receive on-going support to realise further fertility desires, or support to live healthy and satisfying sexual and reproductive lives. Service providers often discourage women living with HIV from having more children, sometimes to the point of being put under pressure to terminate further pregnancies, or strongly advised to undergo sterilisation procedures. Access to comprehensive antenatal services by key affected women remains low, including indigenous women, women in prison, women living in poverty, women who use drugs, women in sex work, lesbian, bisexual or transgender women.

*Especially when it comes to choices about family planning and reproductive choices there is a huge lacuna. Women are often forced to complete families with one child only and those who need termination are often forced to undergo sterilisation procedures along with this. [India]*

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### Overcoming challenges

It is only by investing in the leadership and ensuring the meaningful involvement of women and girls – especially those of us living with HIV and other key affected women – that we can begin to overcome these challenges. Networks and organisations of women living with HIV and other key affected populations exist in all the regions and many are of the countries from which

...greater and more meaningful participation remains hampered by a range of practical concerns and structural factors...

women responded to the survey. Many of these are involved in programmes, and are active in areas, such as information dissemination, treatment literacy, care and support, and advocacy. However, the involvement of these networks and organisations, and their representatives, at the policy or decision-making level, or at the level of research, clinical practice and monitoring and evaluation, remains inconsistent, tokenistic, last-minute, or non-existent. Greater and more meaningful participation remains hampered by a range of practical concerns and structural factors.

*In general people living with HIV in my country are involved in decision-making and prioritisation of key areas of the fight against AIDS. However, women are found most often*

*in the role of carers and recipients of services, rather than decision makers and actively involved in decision-making ... However, initiatives of support and sustainability for people living with HIV have always been a great handicap when limited financial resources, with the emergence of the concept of volunteer indirectly imposed on people living with HIV and less consideration given as a consultant expert in their field of expertise. This should be reflected in future priorities, where the role and expertise of people living with HIV in general, and women living with HIV in particular are recognised and rewarded; they will play a key role if given the space and facilities. [Burundi]*

As we gather in Rome for the 6<sup>th</sup> IAS Conference on HIV Pathogenesis, Prevention and Treatment, it is vital that the words of women and girls living with and affected by HIV are heard. Let these words form the corner stone of constructive dialogue towards building bridges and alliances across the biomedical, legal and human rights, and grassroots and activist communities.

1. The full document can be accessed on [www.wecareplus.net/resources/InWomen%27sWordsFinal.pdf](http://www.wecareplus.net/resources/InWomen%27sWordsFinal.pdf).

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### In Women's Words:

**M**ost people, especially women and young girls, have little or no knowledge about the basic facts of HIV infection, especially in the rural areas where information is sometimes hard to get, and this has resulted in women and girls falling vulnerable to HIV infection on a daily basis. Educating these women on the basic facts about HIV in the rural areas, will help to prevent new infections and eliminate ignorance, which usually leads to vulnerability of HIV infection.

*[West and Central Africa]*

### In Women's Words:

**F**emale condoms continue to be more expensive and less readily available than male. Women living with HIV outside of activist communities, or without good access to support groups and information may not be aware of the existence or development of new female centred technologies, their implications, or the debates around them.

*[North America and Western Europe]*

## Women's Realities...

Fiona Hale and Marijo Vazquez

# Addressed as a continuum...

## Violence against women living with HIV

*The issue of violence against women is one thing and against women living with HIV is another. All the women living with HIV in my organization have been subjected to various forms of violence before and after diagnosis, from sexual violence, psychological, economic to institutional violence. The most important lesson for us is that we are able to talk about this issue and from identification [of it], support each other and make joint decisions to seek help and improve our quality of life. A woman living with HIV who is subjected to violence of any kind is potentially a woman who abandons her treatment and dies. [Argentina]<sup>2</sup>*

There is a growing awareness of the link between HIV and gender-based violence, and of the importance of addressing violence 'as an integral part of multisectoral HIV responses'<sup>3</sup>.

Until recently, work linking HIV and violence against women focused on how violence negatively impacts on HIV prevention. Current definitions of gender-based violence or violence against women do not fully encapsulate HIV positive women's experiences of violence.

We propose a definition of violence against women living with HIV as

*...any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.*

This follows an understanding of violence as something, which is used to achieve and assert power and control over others, and becomes accepted (to greater or lesser degrees) as part of normal social structures.

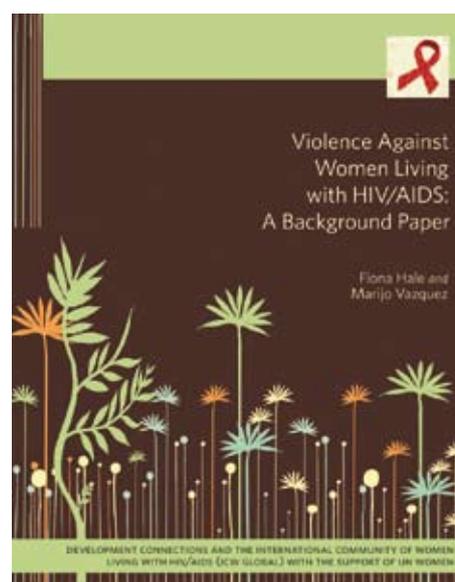
This structural violence manifests itself as 'disparate access to resources, political power, education, health care, and legal standing'<sup>4</sup>. It is reinforced by cultural violence, or

*...aspects of culture... – exemplified by religion and ideology, language and art, empirical science and formal science ... – that can be used to justify or legitimise direct or structural violence<sup>5</sup>.*

Global population surveys indicate that between 15% and 71% of women have been physically or sexually assaulted by an intimate partner at some time in their lives.<sup>6</sup> A recent study<sup>7</sup>, using data from 96 countries, shows that intimate partner violence doubles women's risk of contracting HIV.<sup>8</sup>

When intimate partner violence is part of the backdrop to HIV, we can assume it remains part of the story after testing. Yet, this and the range of other types of violence which HIV positive women experience remain a hidden phenomenon.

Eviction; partner violence; barring women from seeing their children; maltreatment by service providers; police violence, abuse and extortion; loss of livelihoods ... these are all avoidable, unnecessary, and result



**...current definitions of gender-based violence or violence against women do not fully encapsulate HIV positive women's experiences of violence...** in direct and tangible harm to HIV positive women. But violence against women living with HIV also takes a more indirect form.

The use of discriminatory language; legislation and policy, which is developed without using the lenses of gender and HIV status; clinical trials, which do not adequately respect women's autonomy, humanity and rights; the dominance of Western scientific understandings of 'evidence'; institutional failure to understand the realities of HIV positive women's experiences and to create supportive environments – these are equally damaging, and create a structural and cultural climate in which violence against women living with HIV is accepted, to the extent that it is not even recognised for what it is.

Information on violence against women living with HIV can be

difficult to find. This is partly because it is often placed under the headings of stigma and discrimination, access to services, HIV testing, sexual and reproductive health, or adherence to treatment. It may be framed as a 'lack' of capacity, of access, or of informed consent. The terminology used, with its suggestion of technical deficits, neutralises what are often clear manifestations of structural, cultural and/or direct violence against women living with HIV.

The reinterpretation of violence from the perspective of women living with HIV proposed by Nizarindandi Picasso<sup>9</sup> of ICW Latina considers structural, cultural and direct violence and emphasises a life-cycle approach, in which the different forms of violence experienced by women living with HIV throughout their lives must be addressed as a continuum.

### Partner violence

*I was taken to A&E [Accident and Emergency] for head injuries after he punched me and I passed out. I could not tell anyone because he kept threatening to tell friends and family about my HIV status so I remained with him and the abuse. [Patience]<sup>10</sup>*

Women with violent partners in South Africa were more than 50% more likely to be HIV positive than other women<sup>11</sup>. In Tanzania, young HIV positive women were 10 times more likely to report partner violence than young HIV negative women<sup>12</sup>, and HIV positive women identified domestic violence as 'one of the most prevalent problems linked to HIV'<sup>13</sup>.

A WHO study found that in the USA, 20.5% of women living with HIV reported physical abuse because of their status, and in Kenya, 19%

of women reported partner violence because of their HIV status.<sup>14</sup>

In a Zambian study, HIV positive women with violent partners had serious difficulties accessing and adhering to HIV treatment because of violence. Many women were missing doses because of violence from their partners, and then facing judgemental treatment from health workers who blamed them for poor adherence.<sup>15</sup>

*I started taking medication in 2006. My husband does not know. I take the medicine out of a bottle and put it in a plastic bag or in a paracetamol box ... Sometimes I would miss a dose; he comes back at 18.00 hrs, drunk, closes the door and says, 'Today you are going to freak out'. He locks me in, he beats me up and locks me out of the house. ... I go to the neighbours, if they have mercy they will let me in, if not, I sleep under a tree until tomorrow. As a result of that I miss doses sometimes. I feel very bad. I don't even feel like taking the medicine. [Berta K., Lusaka]<sup>16</sup>*

Partner violence may prevent HIV positive women 'from accessing treatment, thus potentially leading to infection of her children, death herself, and/or orphan status for her offspring'<sup>17</sup>.

### Family/in-laws

In India, HIV positive women are usually blamed for their husband's death and are often evicted from their houses, with one study putting the numbers of women experiencing this as high as 91%.<sup>18</sup>

The family setting is also the site of violence when it comes to exclusive breastfeeding or avoidance of breastfeeding<sup>19</sup>, with mothers

facing pressure and questioning from family and others about their feeding choices<sup>20</sup>.

### Health services

Medical care can also be a setting where HIV positive women experience violence, abuse and lack of respect. A recent UK study carried out by Positively Women (now Positively UK)<sup>21</sup> found that 60% of interviewees would not tell their doctor about their HIV status, because of the fear of judgmental treatment or breaches of confidentiality. Health services may be particularly unwelcoming places for sex workers and women who use drugs.

Routine antenatal HIV testing can also be problematic. A US study<sup>22</sup> found that 35% of their sample of women testing positive in pregnancy experienced discriminatory healthcare, compared to none of the women sampled who tested negative in pregnancy.

HIV positive women may also face problems in the labour ward. Studies in India and Nepal found that women were being told to wait until all other women had been delivered: 'If I touch you and then I deliver other women's children, the virus will be transmitted to them. I just do not care what you go through'<sup>23</sup>.

Also in India and Nepal, HIV positive women attending reproductive health services were pinched, punched and scolded by health workers during procedures, because of their HIV status.<sup>24</sup> Five out of seven women interviewed in Delhi were denied abortion or sterilisation services in government hospitals because of their HIV status.<sup>25</sup>

On the other hand, there is evidence of HIV positive women undergoing forced or coerced sterilisation and/or termination of pregnancy, including evidence from Namibia, Thailand and Chile.<sup>26</sup>

...different forms of violence experienced by women living with HIV throughout their lives must be addressed as a continuum...

### Addressing violence against women living with HIV

There are many examples of HIV positive women and their allies organising to address violence against women living with HIV. The most interesting projects seek to incorporate primary prevention (preventing violence before it occurs), as well as secondary prevention ('approaches that focus on the more immediate responses to violence, such as pre-hospital care, emergency services or treatment for sexually transmitted infections following a rape') and tertiary prevention ('approaches that focus on long-term

care in the wake of violence, such as rehabilitation and reintegration, and attempt to lessen trauma or reduce long-term disability associated with violence<sup>27</sup>. This makes them innovative: until recently, most responses focused on secondary or tertiary prevention.<sup>28</sup>

Addressing violence against women living with HIV without taking into account the wider context in which this violence takes place will only limit the extent to which our solutions will address the issue. Favouring expediency over complexity can only give short-term gains. It is vital that work to address violence against women living with HIV is linked to work to build and strengthen communities. One can not work without the other. But there is not a one-size-fits-all approach. Any project must start with community dialogue if it is to successfully address the issues and be owned by those involved.

### What next?

When we first talked about gender-based violence, I thought it was just that women were not comfortable with talking because it would entail admitting to abuse. However when we introduced the research on GBV and the paper by Fiona and MariJo at the start of the e-consultations, women admitted that they had not thought about it. They learn to exist and survive, or have even other women label them as aggressive virago, man haters, wicked, for not accepting the norm. The process for change has started and much work lies ahead.

[Olive Edwards,  
GIPA Facilitator]

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## Women's Voices...

Tamil Kendall, Eugenia López-Urbe, Gabriela García-Patiño

# Universal access to reproductive health... Gaps and opportunities for women in Latin America

### Introduction

The synergistic benefits of linking sexual and reproductive health (SRH) and HIV and the need to respond to the sexual and reproductive health needs of women with HIV were recognised almost twenty-years ago<sup>1</sup> and have been promoted by the United Nations system and networks of women living with HIV for over a decade.<sup>2</sup> Yet, global monitoring demonstrates insufficient progress. In 2008, a mere 21% of pregnant women giving birth in low- and middle income countries were tested for HIV, and only 45% of pregnant women with HIV received antiretroviral treatment to prevent vertical HIV transmission.<sup>3</sup> Significant numbers of women with HIV continue to report unmet needs for family

planning and high rates of unintended pregnancies,<sup>4</sup> as well as other sexual and reproductive rights violations.<sup>5</sup> The conversation about women with HIV's right to choose the number and

spacing of their children through accessing assisted reproduction and adoption has barely begun in the Latin American countries studied.<sup>6</sup>

This article explores the current state of policy and practice, and some of the barriers to the HIV and women's health movements in Latin America developing a joint advocacy agenda focused on achieving the UNGASS Declaration of Commitment on HIV and AIDS and the health-focused Millennium Development Goals (MDGs): reducing child mortality (MDG4), reducing maternal mortality and achieving universal access to reproductive health (MDG5), and halting and beginning to reverse the spread of HIV and AIDS (MDG6).

### Methodology<sup>7</sup>

We reviewed reporting on the UNGASS Declaration and the MDGs to assess operational progress towards meeting country commitments to prevent vertical transmission of HIV and providing reproductive and HIV healthcare services in nine Latin American countries. We undertook a content analysis of the current National HIV and Reproductive Health Plans<sup>8</sup>, and conducted in-depth, semi-structured interviews with women with HIV, feminists working in sexual and reproductive health,

national bureaucrats and United Nations functionaries between September 2009 and March 2011 (n=78) in the three sub-regions: North America (Mexico, n= 26); Central America (El Salvador, Guatemala, Honduras, Nicaragua, n=25); South America (Bolivia, Colombia, Paraguay, Peru, n=27). We validated our findings about barriers to accessing vertical HIV prevention and the availability of sexual and reproductive health services with 130 activists in national meetings with women leaders with HIV in El Salvador (n=16); Guatemala (n=12), Honduras (n=23), Nicaragua (n=18), and Mexico (n=42), and at a forum with activists from all sub-regions (n=19).<sup>9</sup>

### Epidemiology

In Latin America, and in all of the countries included in this analysis, the HIV epidemic remains concentrated (less than 1% prevalence among the general population and more than 5% prevalence among vulnerable populations, such as men who have sex with men, injecting drug users, and sex workers). However, the total proportion of women with HIV in the region and in the countries studied is significant: approximately 30% (550, 000) of the 1.6 million people with HIV in the region are women, and there are an estimated 180,000 women with HIV in the countries analysed.<sup>10</sup>

...the region lacks women-focused HIV prevention policies...

UNIVERSAL ACCESS TO REPRODUCTIVE HEALTH: GAPS AND OPPORTUNITIES IN THE HIV RESPONSE FOR WOMEN IN LATIN AMERICA			Bolivia	Colombia	El Salvador	Guatemala	Honduras	Mexico	Nicaragua	Paraguay	Peru	%	
Estimated HIV prevalence in adults 15-49 (2009)			0,20%	0,50%	0,80%	0,80%	0,80%	0,30%	0,20%	0,30%	0,40%	All under 1%	
Estimated number of women with HIV (2009)			3.600	50.000	11.000	20.000	12.000	59.000	2.100	3.800	18.000	Total: 179.500	
HIV Prevention for Women: Actions in the National HIV Plan	Mentions gender perspective		✗	✓	✓	✗	✓	✓	✓	✓	✓	77%	
	Specific, gender-differentiated prevention for women (other than sex workers and pregnant women)		✗	✗	✓	✗	✓	✗	✓	✗	✗	33%	
	Prevention for women of reproductive age		✗	✗	✗	✗	✓	✗	✓	✗	✗	22%	
	Prevention programs focused on the links between gender violence and HIV		✗	✗	✓	✗	✓	✗	✓	✗	✗	33%	
	Prevention programs for young women		?	?	?	?	?	?	?	?	?	0%	
	Prevention for women sex workers		✓	✓	✓	✓	✓	✓	✓	✓	✓	100%	
	Prevention for women with HIV		?	?	?	?	✓	?	✓	✗	✓	33%	
	Prevention for indigenous women and/or women of African descent		✗	?	✗	✗	?	?	?	✗	✗	0%	
	Prevention for women injection drug users		✗	✗	✗	✗	?	?	?	?	✗	0%	
	Prevention for women migrants and/or female partners of male migrants		✗	?	?	?	?	✗	?	✗	✗	0%	
	Prevention for women who are partners of men who also have sex with men		✗	✗	✗	✗	✗	✗	✗	✗	✗	0%	
	Prevention for women deprived of their liberty (prisons, psychiatric hospitals)		✗	?	?	✗	?	✗	?	✗	?	0%	
Preventing Perinatal HIV Transmission and Congenital Syphilis: Actions in the National HIV and Reproductive Health Plans and other relevant guidelines	Women with HIV who received antiretrovirals during pregnancy to prevent vertical transmission according to UNAIDS (low and high estimates)		2007	12-13%	4-9%	12-32%	5-12%	19-79%	3-7%	15-44%	17-57%	28-56%	UNGASS Goal (2010): 80%
			2009	22-83%	13-55%	19-71%	15-56%	20-82%	3-9%	45-95%	38-95%	33-95%	
	Prevention of Vertical HIV Transmission in the National HIV Plan		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100%
	Prevention of Vertical HIV Transmission in the National Reproductive Health Plan		✓	✓	—	✗	✓	✓	✓	✓	✓	✓	77%
	Prevention of Congenital Syphilis in the National HIV Plan or other HIV Guidelines		✗	✓	✓	✓	✓	✓	✓	✓	✗	✓	77%
	Antiretrovirals during pregnancy		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100%
	Provision of breastmilk substitutes for 6 months		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100%
	Guidelines for cesarean delivery		✗	✓	✓	✓	✓	✓	✓	✗	✓	✓	77%
Guidelines for vaginal delivery with viral load below 1000 copies		✗	✗	✗	✗	✗	✓	✗	✗	✓	✓	22%	
Sexual and Reproductive Health of Women with HIV: Actions in the National HIV Plan and other relevant guidelines	Plan mentions the sexual and reproductive health of women with HIV		✗	✓	✗	✗	✗	✗	✓	✗	✓	33%	
	Guidelines for family planning for people with HIV		✗	✗	✓	✗	✓	✓	✓	✗	✓	55%	
	Female Condom		✗	✗	✗	✗	✗	✓	✗	✗	✗	11%	
	Pap Smear/ Cervical Cancer treatment for women with HIV		✗	✗	✗	✗	✗	✗	✗	✗	✗	0%	
	Diagnosis and treatment of other sexually transmitted infections		✗	✗	✓	✗	✗	✓	✗	✗	✗	22%	
	Adoption by people with HIV		✗	✗	✗	✗	✗	✗	✗	✗	✗	0%	
	Access to assisted reproduction for people with HIV		✗	✗	✗	✗	✗	✗	✗	✗	✗	0%	
	Provision of HIV care with a gender perspective		✗	✗	✗	✗	✗	✗	✗	✗	✗	0%	

**HIV Prevention**

While only Guatemala and Bolivia fail to mention a gender perspective in their National HIV Plans, the region lacks women-focused HIV prevention policies, with the exception of programmes for sex workers and pregnant women. The few countries that mention HIV prevention for women from the general population (El Salvador, Honduras, and Nicaragua) only consider women of reproductive age in the context of perinatal HIV prevention. National HIV Plans do not define gender differentiated prevention strategies for women from vulnerable populations, women in stable relationships,

or women who experience gender violence, despite international research indicating that most women acquire HIV within marriage and associating sexual and physical intimate partner violence with HIV infection.<sup>11</sup> All of the countries have legislation which addresses some aspects of gender violence, but interviews indicate that health services do not systematically identify violence during prenatal care or as a routine part of HIV care.

Only one country (Mexico) includes the female condom in its National HIV Plan. Honduras, Nicaragua and Peru are the only countries which specifically mention

secondary prevention (positive prevention) for women with HIV.

It is clear that the HIV prevention needs of women and girls are not being adequately addressed, even on paper.

...it is clear that the HIV prevention needs of women and girls are not being adequately addressed, even on paper...

There is an urgent demand for specifically tailored, gender-sensitive HIV prevention for women throughout their lifespan, and not solely in their reproductive role (pregnant women) or when they are wrongly perceived as representing a threat to public health (sex workers). A human rights approach demands HIV prevention to promote women's own health.

### Preventing vertical HIV transmission

All of the National AIDS Programmes aim to eliminate vertical (parent-to-child) HIV transmission (100% coverage). According to UNAIDS, all of the countries studied, except Mexico, made significant improvements in the delivery of antiretroviral treatment to pregnant women with HIV between 2007 and 2009. Unfortunately, the lower range

**...a human rights approach demands HIV prevention to promote women's own health...**

Stakeholders stated that pregnant women with a confirmed HIV diagnosis receive antiretrovirals, indicating that lack of HIV testing during pregnancy remains an important barrier to preventing vertical HIV transmission.

Guidelines to offer HIV testing to pregnant women exist in all the countries and half of the countries (Colombia, El Salvador,

Honduras and Nicaragua) have guidelines which make that *offer* obligatory; it is of concern that two countries (Bolivia and Peru) have made the HIV test *obligatory* for pregnant women.

In practice, centralisation of services where testing is offered, stock-outs of rapid tests and reagents, and user fees for healthcare services limit effective access to HIV testing for women, during pregnancy and in general. Limited knowledge of women's vulnerability to HIV and low risk perception by physicians and women are additional barriers.

All of the countries have adequate clinical guidelines for preventing vertical HIV transmission (combination antiretroviral therapy, breast milk substitution, and in most cases, guidelines for caesarean delivery). But in practice an enabling environment which allows women with HIV to make informed choices and implement them is lacking. Guaranteed access to free breast milk substitutes is not universal. Clinical guidelines propose formula feeding without ensuring counselling that addresses the socio-economic and cultural realities that can be barriers to breast milk substitution. Infant-feeding counselling for women with HIV needs to explore the relative risks and benefits of breast and formula feeding, and emphasise the need to avoid mixed feeding.<sup>12</sup> Women with HIV continue to be denied programmed caesarean delivery by healthcare providers who are not specialised in HIV. Finally, only two countries (Mexico and Peru) include the option of vaginal delivery with a viral load below 1000 copies. None of the countries have disseminated the possibility for vaginal birth, among treatment

physicians or networks of women with HIV, widely.

### Sexual and reproductive health and rights of women with HIV

Important gaps in achieving national and international commitments to sexual and reproductive health and rights persist, as does the need to integrate HIV with sexual and reproductive health services. Stigma and discrimination, which deny the sexual and reproductive life of women with HIV, contribute to violations of the right to decide about the number and spacing of children and thus prejudices the sexual and reproductive health of positive women.

Even though half of the countries mention family planning for women with HIV in relevant clinical guidelines, only one (Nicaragua) considers contraceptive use by women with HIV in the National HIV Plan. According to the stakeholders consulted, none of the countries offer comprehensive family planning counselling as part of HIV care. Assisted reproduction and adoption are absent from all of the National HIV Plans. Likewise, the diagnosis and treatment of other sexually transmitted infections (except syphilis to avoid congenital cases) is overlooked, except in El Salvador and Mexico.

**...but in practice an enabling environment which allows women with HIV to make informed choices and implement them is lacking...**

In practice, access to diagnosis and treatment of sexually transmitted infections, including regular pap smears, is unequal between countries and across health service delivery systems – access depends more on the knowledge and commitment of the treating physician, than on institutional or country level policy.

### The political context<sup>13</sup>

The multiple benefits of implementing prevention of vertical HIV transmission (providing women with HIV with a timely

**...based on their lived experience, women with HIV perceive SRH/HIV integration as a priority...**

diagnosis and access to treatment; increasing HIV-negative women's awareness of HIV and knowledge about HIV prevention; potentially providing timely diagnosis to male partners

and other children) and a comprehensive conception of the sexual and reproductive health needs and rights of women with HIV are marginalised discourses among decision-makers, HIV activists and feminists working on sexual and reproductive health in the region. The narrow and divisive framing of prevention of vertical HIV transmission in terms of infant health versus women's rights, rather than promoting the health of women, children and the community, and tensions over funding between SRH and HIV civil

society, government programmes and UN agencies are significant impediments to the SRH/HIV integration agenda. International reviews have vindicated the generally positive effects of investments in HIV for health systems and demonstrated positive results of strengthening linkages between SRH and HIV for the quality of service delivery, and some initial cost-benefit analysis.<sup>14</sup>

Based on their lived experience, women with HIV perceive SRH/HIV integration as a priority, but have faced challenges in attracting institutional support and political priority from the HIV and women's health movements. Within networks of people with HIV, different perceived needs and priorities from the predominantly homosexual male membership are barriers to prioritising prevention of vertical HIV transmission and SRH/HIV integration. While feminists, including the authors, are working with women with HIV at the country and regional level, generally speaking these are recent collaborations that in most cases are only starting to generate an articulated advocacy agenda. Identified barriers to collaboration include the continued perception that HIV is not an important women's issue among feminists, HIV-related stigma, class differences, and lack of knowledge about the international conferences that form the backbone for the feminist SRH agenda among women with HIV. One of the key problems identified was that when feminists did work on HIV, they frequently did so without the meaningful involvement of HIV positive women. The Greater Involvement of People Living with HIV and AIDS (GIPA) principle<sup>15</sup> can be an effective antidote to

feminist perceptions of women with HIV as 'other' and broaden understandings of the benefits of preventing vertical HIV transmission and SRH/HIV integration.

Collaborative advocacy is necessary to ensure that the new HIV and Reproductive Health Plans written in the region include primary HIV prevention for all women, promote the sexual and reproductive rights of women with HIV, and fully operationalise programmes to prevent vertical HIV transmission, while respecting women's rights, and to achieve the targets committed to by country governments in the Millennium Development Goals and the June 2011 Political Declaration on HIV and AIDS.

### Recommendations

- Develop and implement specific prevention campaigns for women that recognise gender differences and highlight women's vulnerability to HIV infection throughout the lifecycle, not only during pregnancy.
- Guarantee access to free and voluntary HIV testing as a routine part of prenatal care by making the offer of HIV testing with informed consent an obligation for healthcare personnel.
- Update clinical guidelines and begin a multisectoral dialogue on the benefits of vaginal delivery when the viral load of a pregnant woman with HIV is below 1000 copies.
- Ensure comprehensive counselling on infant feeding, which explores the context of women's lives and supports them to make informed decisions

and to achieve exclusive formula or breastfeeding.

- Create a favourable environment for the exercise of reproductive rights by women with HIV. Needed steps include guaranteeing access to counselling and a full range of appropriate contraceptive methods in addition to the condom (dual protection) for women who do not want to become pregnant. Women with HIV who want a child need objective information and medical interventions to permit safe and healthy conception and pregnancy, or if they prefer, support to adopt.
- Guarantee diagnosis and treatment of sexually transmitted infections, including the Human Papilloma Virus (HPV), as a routine part of HIV care.
- Systematically identify and respond to gender violence during prenatal care, HIV pre and post-test counselling, and as an integral part of HIV care.
- Increase financing to support and expand peer support and advocacy by women with HIV to improve implementation of perinatal HIV prevention, sexual and reproductive health, and women's self-care before, during, and after pregnancy.
- Carefully analyse mechanisms for integrating HIV and sexual and reproductive health services to ensure that such efforts respond to health system specificities and the socio-cultural context of each country.
- Guarantee the sustainability of perinatal HIV prevention beyond the

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8. Content analysis of National HIV and Reproductive Health Plans, as well as the

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Dianne Massawe and Pamela Chakvinga

# Special report:

## Their voices need to be heard...

### Barriers to healthcare as experienced by sex workers

A growing body of evidence indicates that criminalisation of sex work is harmful to public health efforts to prevent the spread of HIV and other sexually transmitted infections<sup>1</sup>. The African Sex Worker Alliance (ASWA) commissioned a study to document sex workers' experiences of human rights violations and barriers to accessing healthcare in four African countries; Kenya, South Africa, Uganda and Zimbabwe.

In all of these countries some aspects of sex work, if not all, are criminalised, like in many other African countries. In Kenya, selling sex is penalised but not the purchase, which means that sex workers who are predominantly women are criminalised and not their clients; in South Africa, all aspects of sex work, including selling, buying and living off the proceeds of sex work, are criminalised; in Uganda, selling and living off the proceeds are illegal but not the purchase of sex work; and in Zimbabwe, solicitation for the purpose of sex work is criminalised. Sex workers are criminalised in all these countries.

Since sex work is criminalised many sex workers face gross human rights violations, discrimination and violence, and experience a number of challenges and barriers when trying to access services, especially health services at state facilities. These violations are not unique to Africa, but to countries where sex work is criminalised, as the industry and those operating in it are stigmatised and discriminated

against, due to the moralistic views that society has and the fact that the law renders sex workers 'criminal'.

Due to the lack of recognition of sex work and sex workers' rights, many sex workers across the globe face numerous human rights violations from a range of actors, including the police who are meant to serve and protect; health care workers who are meant to provide judgement-free health services; religious institutions; their clients; and their families, friends and communities when they discover that they are doing sex work. At times, the violations extend to their children in the form of name calling and labelling: 'when they see my child they say 'that's a prostitute's child, look at it'<sup>2</sup>.

For sex workers in many countries the police are among the last people they can turn to when their rights have been violated, as it is, at times, the police who are the ones violating sex workers' rights. Many sex workers fear the police, due to the violence and abuse, including rape, perpetrated by the police against sex workers.

*Recently the military police raped sex workers in Kisenyi and they had unprotected sex, but the sex workers refused to go to the police. They asked themselves 'how are we going to report this case, that this time around we have been raped by the military police'?*

[Female sex worker, Kampala]<sup>3</sup>

*I was escorting my client to his car after his massage and there were plain-clothes policemen...three of them. Just as he drove off, they came and I thought they were thieves trying to take money so I tried to explain to them no I am not carrying anything; only to discover that they were policemen. There's a car park next to the flat and they took me there and they took turns.*

[Female sex worker, Bulawayo]<sup>4</sup>

Gross human rights violations perpetrated by the police also increase sex workers' risks to contracting HIV or other sexually transmitted infections. In order to be able to access post-exposure prophylaxis (PEP), one needs to lay a charge of rape and get a medical examination. How does one go to report a rape at the police station when the perpetrator of that action is the police? The chances are that these crimes by and large go unreported and the sex workers are not in the position to access PEP and other treatment after the rape.

#### Sex work and health

*We are despised in the hospitals. They say, 'We don't have time for prostitutes' and they also say that if one prostitute dies then the number reduces.*

[Female sex worker, Kampala]<sup>5</sup>

The most common ideology when discussing sex work and health is that sex workers are 'diseased', and they are the ones to blame not only for the failure of marriages, but also for the spread of HIV and other sexually transmitted infections. It is because of assumptions like these that sex workers are ill-treated when trying to access health services. The reality is that many sex workers are aware of how to protect themselves from being infected and from transmitting the virus, but they often do not have the power or the means to do so, as many clients will force sex workers to have unprotected sex and/or offer higher prices for sex without a condom<sup>6</sup>.

*I know a lot of men like that [unprotected sex] but if you are*

...violations are not unique to Africa, but to countries where sex work is criminalised...

*principled, you stick to the principle of no condom, no sex.*  
[Female sex worker, Bulawayo]<sup>7</sup>

In addition, although many sex workers have the knowledge of how to reduce the risk of transmission, they have poor access to healthcare and HIV prevention technologies, due to their exclusion from public campaigns for safer sex and their limited access to health services in general, due to stigma and discrimination. For many sex workers, the much needed information, support and services are received mainly from non-governmental organisations that have a minimal reach, due to limitation of funds and coverage, as compared to state facilities<sup>8</sup>. In the study by Scorgie et al<sup>9</sup> many sex workers said that they made use of facilities that they knew catered for sex workers or were sex worker friendly, but these facilities are located only in some places and meet the needs of the few who are located near them. The discriminatory attitude and mal-treatment sex workers experience in clinics and hospitals often deter sex workers from accessing the much-needed services.

*When I fell sick and went to a health centre and they realised that I was a sex worker, they did not treat me like a human being. When the health worker came to attend to me she said that I should go to the other health worker and when I reached the other health worker, I was told that he had no time for me so I left without getting treatment.*  
[Female sex worker, Kampala]<sup>10</sup>.

For sex workers to be in the position to work safely and to minimise contracting HIV and other STIs, they need comprehensive HIV prevention technologies, such as female and male condoms, dental dams, gloves, and lubricant, that are free and easily accessible, and that will not be used as a means to arrest them.

*I have always seen many of my friends insist on condoms. As a woman I have a choice of the female condom. Many of my clients prefer using the female condom; they complain that the male condom is too tight for them.*

[Female sex worker, Bulawayo]<sup>11</sup>

*There is one male worker [at the clinic] who brings condoms for me and ask me to have sex with him because he brings me something so I must have sex with him.... it means it's not for free, you have to exchange it with something.*

[Female sex worker, Musina]<sup>12</sup>

### Conclusions

In order to minimise sex workers' risks of infection of HIV and other STIs, their voices need to be heard and services need to cater to sex workers' needs. For the sex workers who participated in this study their needs range from law reform, so that their work is recognised as work and they are no longer viewed as criminals, to better access to healthcare, not only for themselves, but for the public.

There is also a need for

people-friendly, stigma and value free services that all people, including sex workers, can access without the fear of being stigmatised, discriminated against and abused. We need services that protect the human rights and dignity of all people, as this will promote the uptake of services, and thus further public health efforts to halt the spread of HIV.

Lastly, there is as much the need for solidarity with sex workers and support for sex workers' rights, as there is the urgent call to ensure that all women are in the position to access the sexual and reproductive health services they need and are entitled to.

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...the reality is that many sex workers are aware of how to protect themselves from being infected and from transmitting the virus...

### In Women's Words:

**E**nsure adequate information, training, support, and remuneration for women and girls who are care-givers, including mothers, volunteers and older carers, and women and girls living with HIV.

[East and Southern Africa]

Ebony Johnson

## In my opinion...

# A collective yearning for universal access...

**It was very positive to open the High Level Meeting on AIDS in June 2011 with *In Women's Words* on Tuesday, 07 June 2011, the eve of this important global meeting. The survey and event was an excellent example of effective partnership between civil society and global planning mechanisms.**

The event launched the Athena Network, UNAIDS, GCWA and UN Women virtual consultation results.<sup>1</sup> It was excellent to have a document capturing the anecdotal realities of women that inform the empirical values determining funding, resource allocation and targets for girls and women in National AIDS Strategies. The survey and ensuing processes also highlighted how imperative the inclusion of women, and women living with HIV, in national, regional and global HIV responses.

For many of the nearly one thousand women who participated in the survey who sat divided from policy, planning or even modest mechanisms, to give voice to their realities; this was the time and this was the moment that their pain,

social trials, daily struggles against the tide of inequality and desperation for change could turn poison into medicine and inform new realities through the High Level Declaration on Universal Access. From small villages to urban epicentres, women shared realities of blistered feet walking to dismissive providers riddled by stigma and women living with HIV desperate for access to care. Women shared their most intimate struggles for universal access, their most tender hopes for change, and their most robust calls for government to change the tide in human rights and HIV treatment, care and prevention. The survey yielded five key points developed in an Action Agenda.

The **Action Agenda** presented at the launch included the following:

1. Ensuring comprehensive and inclusive HIV services that address the visions, life-long needs, and rights of women and girls in all our diversity.
2. Eliminating stigma and discrimination, and ensure full protection of the human rights of all women and girls, including our sexual and reproductive rights.
3. Strengthening, investing in, and championing our (women and girls) leadership and

...women  
shared their  
most...robust  
calls for  
government to  
change the tide  
in human rights  
and HIV...

...social  
climates that  
dismiss and  
deny the rights  
of women  
living with HIV  
to be sexual,  
mothers  
and healthy  
women...

equality, to ensure the full and meaningful participation of women and girls, in particular those of us living with and affected by HIV, in the HIV response.

4. Empowering us (women and girls) to be catalysts of social justice and positive change, and eliminate all forms of violence against us.
5. Ensuring full access to information and education, including comprehensive sexuality education for all women and girls.

These were the five key messages that loudly resonated from the virtual consultation echoed from region to region passionately, sincerely, and with a collective yearning for universal access to HIV prevention, treatment and care for all women and girls everywhere.

While the launch was an excellent means of highlighting issues of women globally and informing future HIV responses, sadly, we did not see the language adopted in the High Level Declaration itself. While paragraph 53 had excellent language for women and girls, it was not as expansive as many of us had hoped. Much of the language was that

which had been previously included in the 2006 Declaration.

In particular, there was no reference to the necessity for sexual and reproductive health services and rights for women living with HIV. This is disheartening as women living with HIV face compounded challenges of gender inequity, HIV-related stigma and discrimination, inability to negotiate safer sex, forced sex by primary partners and husbands who leverage housing and other financial supports, coercive providers and social climates that dismiss and deny the rights of women living with HIV to be sexual, mothers and healthy women.

Throughout the HLM process there was a propensity to link SRHR for women with prevention of vertical transmission programmes that are geared toward infant health and viability, which grossly misses the mark on providing comprehensive services to all women throughout their lifespan. Women and girls living

with HIV want, need, and deserve access to sexual and reproductive health services, prevention services and comprehensive sexuality education. These services and compassionate provider delivery are imperative to women living with HIV being in control of the number, timing and spacing of their children, as well as preventing unplanned pregnancies, treating and assessing sexually transmitted infections, and maintaining their reproductive health. Health is a human right for all, not a luxury deemed by HIV status, occupation, drug history or age.

Despite all of this, it was, indeed heartening in the panels and side session to have governments, including Rwanda, Portugal, Mexico, Liberia and St Martin make robust and welcomed calls for micro-financing for women and girls; prevention innovation; funding for civil society as community healthcare providers; TRIPS flexibilities; acceleration of female condom provisions and

...not as  
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programming; human rights; women's rights; access to generic drugs; acknowledgement that healthy children need healthy mothers; mothers need access to care, treatment and support beyond vertical transmission services.

While it was amazing to hear championing for women health, rights and quality of life; the amazing panels, presentations, side meetings, rousing speeches and glorious calls to actions were all needed in advance of the negotiations wherein they could have made practical and substantial impact on the negotiation and the outcome document. This was sadly just an example of one of the many disconnects and missed opportunities of the HLM process.

1. The outcome document of the Virtual Consultation, *In Women's Words*, can be accessed on [www.wecareplus.net/resources/InWomen%27sWordsFinal.pdf](http://www.wecareplus.net/resources/InWomen%27sWordsFinal.pdf)

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## In Women's Words:

I am not promoting, I live with HIV, but only at our centre – The Centre for Mental Health and HIV – I have received everything necessary. There is a paediatrician here who takes care of my children; there is a physician here who takes care of me. I live with hepatitis C; there is an ultrasound scanner at our centre, and I have the scanning done for free. We have a gynaecologist, she consults and examines me regularly, we even have a colposcope. And I can access all these services any time for free. I receive advice from my gynaecologist on sexual health, since my partner also lives with HIV. I receive condoms here; I even learnt about female condoms at our centre for the first time and received my first one here. When I or my children fall ill, I am provided with massage and physiotherapy services at our centre – ultraviolet irradiation, UHF-therapy, ozokerite and paraffin applications. All women coming to us have access to such services. This is the first such centre in Tajikistan. We are an NGO; we just have a healthcare centre which provides services to general public. At the same time, HIV+ people are also openly serviced – in other words, HIV+ women are not afraid to disclose their status. We do need such a centre. This is the only place in our country which provides everything necessary for a woman. When our women are preparing for delivery, they are provided with trainings and with milk for newborns. Then our paediatrician monitors the babies and adjusts nutrition where necessary. We are also tested for hepatitis and TB here and receive social support.

[Tajikistan]

## In Women's Words:

**S**tigma associated with HIV positive women, women in sex work etc, etc is a huge impediment to prevention; sex worker's clinics should be run by sex workers [Kenya]

**T**he condom system fails to recognise the fact that for it to be effective both parties must agree and understand its use, most time the woman has no say in the relationship and cannot insist her partner uses condom, she is also unaware of the female condom, can't afford it or she is afraid of the trouble it will stir, as female seen with condoms are termed promiscuous.

[West and Central Africa]

**W**ithin Asia-Pacific there is still a great deal of coerced abortion, sterilisation and refusal of abortion – i.e. many women have no reproductive choices available to them. [Australia]

**H**IV testing is offered only to pregnant women and usually without informed consent, and without pre and post test counselling, regardless of the outcome. In many places in our country the confidentiality of a woman living with HIV is not respected, exposing them to stigma and discrimination; not only her but everyone around her, especially her daughters and sons and even more so if they are also living with HIV. It is very common for people to travel long distances to get tested for HIV, so that this information is not divulged in their place of residence.

[Argentina]

**W**omen from marginalised groups will not reveal their profession or drug habits to health workers for fear of being stigmatised. Women from marginalised groups will not discuss their situation with health workers. Stigma and discrimination among health workers is the biggest obstacle for women to access health services if they are HIV positive. [Malaysia]

**T**here is just the beginning of discussion re NPT [new prevention technologies], but this is mostly in the print media, which is not always accessible for all women. At present microbicides are stigmatised in Zambia, because of inaccurate reporting post the MDP 301 trial results which were misconstrued for political gain. At present both men and women likely believe that microbicides give people HIV and that any further research on microbicides has been banned as per the bold press headline of Jan 2010. There will be a long uphill battle to have people have open minds about and be able to understand research and NPTs. [Zambia]

**H**IV/AIDS is very much a gay agenda item in the US, and there are women's issues addressed but not in proportion to the numbers of women affected by HIV. Right now, right-wing political efforts to prevent access to abortion and birth control and requiring parental notification are growing and receiving support, jeopardising youth's ability to make autonomous decisions about reproduction. This is compounded by the erosion of sex education, leaving youth unprepared for sexual experiences, which they (and most people) actively seek. [US]

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