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## Beyond the recognition of human rights...

Violence against women and HIV: Ethical policy and programme development

*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. (Latin America)<sup>1</sup>*

**Fiona Hale, MariJo Vazquez, Dinys Luciano**

**A**s understanding of the links between HIV and violence against women grows, so too does the ethical imperative for policies and programmes which integrate both issues; addressing them together, rather than in isolation. Key considerations include how to ensure service delivery, treatment and prevention, research, and programme and policy development which integrate HIV and violence against women, addressing the priorities of women and girls who

are living with HIV and/or experiencing gender-based violence, upholding their human rights and challenging gender inequalities.

These are some of the key questions which are explored in the project *Human rights, HIV and violence against women in Central America: Integrated Responses*, which takes place in four countries in Central America, and which is led by the Inter-American Commission of Women of the Organization of American States. The document '*Ethical considerations for an integrated response to human rights, HIV and violence against women in Central America*', produced as part of this

*Mujeres Adelante*

A NEWSLETTER ON WOMEN'S RIGHTS AND HIV

# Editorial...

**M**oving towards the International AIDS Conference in Washington, DC, in July 2012, this special 'pre-conference' edition of the *ALQ/Mujeres Adelante* on women's rights and HIV portrays some of the realities, risks and needs of women and girls in various contexts and locations.

The various articles explore the extent to which progress has been made in 'realising' women's rights in the context of and in the response to HIV, with a particular focus on accessing services and programmes; and highlight the many challenges women face when claiming their rights and accessing services. Some of the issues discussed include the need for ethical policy and programme development when addressing the intersection of violence against women and HIV; the opportunities and implications of the healthcare reform in the U.S. for women living with HIV; the effects of patriarchy and gender inequality on HIV testing and disclosure in South Africa; positive women's experiences of accessing reproductive and maternal health services in six Asian countries; and the need for effective HIV responses to the realities and needs of key affected women and girls in Asia and the Pacific. This edition also provides an overview of women's realities versus rights in the context of women and HIV in Africa, and explores the 'threats' to achieving women's health and rights in times of economic austerity.

In light of the growing understanding of the links between violence against women and HIV, as well as more programming integrating both issues, **Fiona Hale, MariJo Vazques** and **Dinys Luciano** discuss the ethical imperatives and principles which are to be applied in policy and programme design and implementation. The article explores the role of ethics in relation to human rights and the law, as well as to violence against women and HIV, and introduces ethics as the cornerstone of participation. Based on the premise that even 'well-intentioned' policies and programmes may 'exacerbate the effects of violence and HIV' and expose women to greater risks, the article argues that we have to move 'beyond the recognition of human rights' and begin to 'cross-fertilise' ethics

*Continued on page 4*

## In this issue

1. **Beyond the recognition of human rights...** **Page 1**  
*Violence against women and HIV: Ethical policy and programme development*  
Fiona Hale, MariJo Vazquez, Dinys Luciano
2. **Editorial** **Page 2**
3. **Speak Up!** **Page 11**  
*Women changing the course of the HIV epidemic*  
Naina Khanna, Brook Kelly
4. **The common mindset...** **Page 20**  
*Gender inequality and its effect on HIV testing and disclosure*  
Sierra Mead
5. **Positive and pregnant ...how dare you** **Page 28**  
*Access to reproductive and maternal healthcare for women living with HIV in Asia*  
Susan Paxton
6. **Messages from around the world** **Page 37**
7. **Critical ingredients for effective HIV responses...** **Page 38**  
*Women and girls in a concentrated epidemic*  
Rodelyn Marte, Rose Koenders, Katy Pullen
8. **Who decides...?** **Page 43**  
*Achieving women's health and rights in times of economic austerity*  
Luisa Orza
9. **Intersecting factors must be addressed...** **Page 47**  
*Sexual and reproductive health and rights, HIV and the African Women's Protocol*  
Karen Stefiszyn
10. **Taking a stand** **Page 56**

project, is among a small number of papers which specifically address this issue.

A decade ago, international organisations working on HIV and women's human rights started sharing evidence of the strong link between violence against women and HIV. A number of international agreements – including the Declaration of Commitment on HIV/AIDS (UN, 2001) and the San Salvador Declaration on Gender, HIV and Violence Against Women (CIM/OAS, 2007) – acknowledged that eliminating violence against women contributes to reducing the spread of HIV. Awareness is growing of the impact of violence against women as something which intersects with HIV throughout the life cycle<sup>2</sup>, and that effective responses to violence must

include and be adapted to the different life cycles of women and men. Whole-system and whole-society approaches are needed:

responses which see men simply as perpetrators of violence against women miss the opportunity to tackle vital underlying structural and cultural causes of violence against women living with HIV, which we define as

**...responses which see men simply as perpetrators of violence against women miss the opportunity to tackle vital underlying structural and cultural causes of violence against women living with HIV...**

*...any act, structure or process in which power is used in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV<sup>3</sup>.*

With the global rise in HIV prevalence among women, and growing awareness of the scale of violence against women, there is increasing support for the idea that ethical policies and programmes on HIV and on violence against women must grapple with

*I am 17. I have a 3 month old baby. I acquired HIV/AIDS from my mother. She had the virus because she was raped by her step-father. He raped her, my aunts, and he had sexual relations with my grandmother, his wife. They all got HIV. My mum could leave, so she did. She left home and got together with my dad when she was 13 or 14. She passed the virus on to my dad without knowing it. . . My little sister is 14 and luckily her health is good, like mine is, but her situation is different to mine – she does not have the virus. . . My mum died when she was 19 and I was 3, and my dad died at 33 when I was 12. . . When my mum and dad had both died, I went to live with my grandmother. At first she treated us well, but as my body started to develop when I was 10, my step-grandfather raped me and my sister. We told my grandmother, but she didn't want to listen. I did not really have a childhood or adolescence.*

**Morena, 19, Panamá<sup>4</sup>**

and human rights approaches, so as to ensure the meaningful involvement of those at the intersection of violence against women and HIV.

The healthcare reform, and its opportunities and implications for women living with HIV in the U.S., is the focus of the article by **Naina Khanna** and **Brook Kelly**. Recognising the potential of healthcare reform to address and reduce '*health disparities*' experienced by women living with HIV, the article discusses a number of reasons as to why the full implementation of healthcare reform is '*vital*' to ensure that the realities and needs of women living with and vulnerable to HIV are more adequately catered for by the healthcare system. The authors emphasise the importance of '*collective advocacy*' and argue that the meaningful involvement of women living with HIV in all aspects of decision-making; ending HIV criminalisation; and securing sexual and reproductive justice, economic justice, prevention justice, and women-centred care, are most critical aspects in '*changing the course of the HIV epidemic*'.

Gender inequality and its effects on HIV testing and disclosure in the

South African context are discussed by **Sierra Mead**. The article, placing patriarchy at the centre, explores the various correlations between male dominance and HIV, and highlights violence and/or the fear violence as a common denominator for women's experiences of HIV testing and subsequent disclosure of a positive HIV status. Underscoring the '*disempowering*' effects of the '*powerful social attitude*' that embraces gender inequalities, and the need for HIV testing services to '*begin to anticipate and address*' possible adverse consequences for women accessing these services, she argues that without changing the '*common mindset*', women will continue to '*avoid*' HIV testing, as the '*benefits*' of knowing one's status outweigh the possible '*risks and consequences*'.

The scale-up of HIV testing during pregnancy is often associated with stigma, discrimination and other rights violations against women living with HIV within service provision. It is within this context that **Susan Paxton** explores positive women's experiences of accessing reproductive and maternal health services in Asia, and introduces key

findings and recommendations from a study in six countries. Analysing women's experiences in accessing a wide range of services, including pre- and post-test counselling, access to antiretrovirals and contraception, pregnancy-related healthcare and delivery, infant healthcare, as well as termination of pregnancy and sterilisation procedures, the findings clearly indicate '*extreme levels*' of discrimination and other rights violations, degrading treatment by health providers, coercive practices, especially in the context of abortion and sterilisation, and lack of information and support for women living with HIV. The article concludes with recommendations, including the need to uphold, protect and advance positive women's rights, while ensuring an end to coercive and discriminatory practices in reproductive and maternal healthcare.

Focusing on key affected women and girls in concentrated epidemics, **Rodelyn Marte**, **Rose Koenders** and **Katy Pullen** explore '*critical ingredients for effective HIV responses*' in Asia and the Pacific. Highlighting that the needs and rights of women and girls most at risk of, and vulnerable to HIV, continue

**...applying ethics in our lives requires us to develop attitudes and behaviours which take into account the possible consequences of our actions...**

women's empowerment and rights, equality, and gender equity, as well as the role of power dynamics in any initiative to address the structural factors common to both violence against women and HIV.

- What do we understand by ethics?
- How does ethics relate to human rights, and the law?
- What is the place of ethics in relation to violence against women and HIV?
- Participation and ethics

**WHAT DO WE UNDERSTAND BY ETHICS?**

Ethics is a set of principles used to reflect on the intentions and consequences of situations and actions aiming to protect individuals and communities, while exploring risks and benefits for them. These principles include concepts such as respect for autonomy of the person, beneficence, non-maleficence and justice, as well as principles such as gender equality, accountability, respect for human rights, women's empowerment and participation.

Violence against women and HIV have both a huge impact on women's access to work, health, justice, education and services in general. In any sector, the policies and programmes which do not take into account the needs of women may exacerbate the effects of violence and HIV<sup>5</sup>. Even when policies and programmes are well-intentioned, they may expose women to greater levels of violence, and/or pose problems for HIV prevention, care, treatment and support for women.

By providing a guide to ethical thinking, multisectoral partnerships will be able to find common ground for ethical decision-making built on the meaningful involvement of those at the intersections of violence against women and HIV – particularly women living with HIV and women with experience of violence.

Below we briefly address the following questions:

Ethical behaviour requires us to link key principles with the particular circumstances in which we find ourselves in our professional, person and social relationships. It is about bringing these principles to life through our individual actions, and making them permeate in everything we do in our personal, professional and social lives.

**...ethical behaviour requires us to link key principles with the particular circumstances in which we find ourselves...**

to be *'side-lined'*, the article underscores the need for more evidence-based research, building strategic partnerships and alliances, mobilising support, and policy advocacy so as to ensure effective responses to women and girls in concentrated epidemics. The authors share their experiences, as well as challenges, and argue that in order to achieve *'commitments and targets'* it is crucial to *'counter the invisibilisation'* of women and girls, to recognise their specific realities and needs, and to ensure that these are *'accurately'* addressed.

Recognising the fact that despite political commitment, women and girls continue to face serious rights violations in the context of access to healthcare, **Luisa Orza** raises the question as to *'who decides'* the extent to which women's health and rights are achievable in times of economic austerity. The article discusses the *'investment paradigm'* and *'chronic underfunding'* for women and girls, and highlights the need to expand the agenda, to reclaim the multiple dimensions of rights, and to demand accountability. Drawing from various women-led conversations and consultations, she argues that it

is time to *'urgently'* realise the political commitments around women's and girls' right to health, and to translate women's rights from the *'imaginary'* to the *'real'*, as otherwise the lived complexities of women's rights and challenges of claiming rights will continue to go *'misunderstood and unacknowledged'*.

The violation of positive women's sexual and reproductive health and rights in the context of HIV in Africa are explored by **Karen Stefiszyn**. Based on the premise that the violation of these rights are cross-cutting and inhibit the enjoyment of other rights, the article introduces positive women's lived realities *versus* the rights guaranteed in the African Women's Protocol in the context of pregnancy, the right to control fertility, family planning and access to contraceptive services, access to legal abortion, as well as forced or coerced sterilisation. Exhibiting the huge gaps between rights and realities, she argues that effective responses to women and HIV in Africa have to be based on enabling environments for women to exercise their rights, and need to address *'intersecting factors'*, such as gender inequality and gender violence, increasing women's risks

and vulnerabilities to HIV and related rights abuses.

The various realities portrayed in the articles, although diverse in their contexts and locations, seem to all underscore the persistence of human rights abuses and violations based on and in the context of HIV, as well as the apparent *'inability'* to translate the commitments to promote and protect human rights in the response to women and HIV into *'lived experiences and realities'* of women and girls. Similarly, despite the variety of women's realities presented in these articles, the common *'picture'* seems to be that without addressing and transforming societal contexts and environments creating and manifesting women's greater risks and vulnerabilities to HIV and related rights abuses, women across the globe will continue to be the *'target'* of stigma, discrimination, violence and other rights violations, despite the many commitments and declarations to protect and advance women's rights in the context of, and in the response to, HIV. Given these seemingly never-changing realities for women and girls, it is indeed high time for **Turning the Tide!**

**JOHANNA KEHLER**

Applying ethics in our lives requires us to develop attitudes and behaviours which take into account the possible consequences of our actions. It means taking responsibility for whatever we do. It is important to note that ethics is not static; it is a process, needing constant assessment to ensure our decisions are keeping up with the changing context, and therefore the consequences, of our actions.

Ethical decision-making is not straightforward. It requires accepting complexity; debate and dialogue with those affected; and understanding of different viewpoints. Ethical decision-making is particularly dependent on personal, organisational and institutional commitment.

**HOW DOES ETHICS RELATE TO HUMAN RIGHTS?**

**AND THE LAW?**

Ethical principles provide standards used both to understand the dynamic of problems and to respond to them. Ethics and human rights are complementary fields, since both focus on human well-being and justice. Ethics engages us in a critical thinking process, while the laws and human rights provide a legal grounding of institutions and individuals in relation to their responsibilities.

**...ethical decision-making is not straightforward. It requires accepting complexity; debate and dialogue with those affected; and understanding of different viewpoints...**

In many countries laws are grounded neither in sound ethical values, such as justice, respect for people and beneficence, nor in human rights principles of non-discrimination, participation and accountability. The law should be inextricably linked to ethics, to a moral (but not moralistic) understanding of the world and the relationships between people. In this way, laws, human rights, and our responsibilities as human beings must be intimately linked, so that

rights are protected by laws which are accepted and acceptable, and not just coercive. There is an urgent need to cross-fertilise ethics and human rights approaches, and to explore how they can be applied in conjunction to the theory and practice of policies, programmes and research.

Including ethical reflection in our work and in our private lives introduces the concept of responsibility for our actions at individual, institutional and community levels. This responsibility is what ensures that human rights are

not only recognised as inherent to our human condition, but also respected and defended. In this same sense, ethical reflection also

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allows us to create better laws, which enable practical interpretations of a series of agreed principles.

Ethics goes

beyond the recognition of human rights, and imposes a moral obligation to defend them and to take the consequences if they are not taken into account, including not just the human rights of individuals, but the principle of social justice, which is by its nature relational and takes account of the community and society in which people live.

#### **WHAT IS THE ROLE OF ETHICS IN RELATION TO VIOLENCE AGAINST WOMEN AND HIV?**

Ethics and human rights frameworks are key to the development of integrated responses to HIV and violence against women:

- There is a great need to determine an appropriate course of action to ensure ethical principles, such as social responsibility, justice, respect for persons (privacy, confidentiality, informed consent), beneficence and non-maleficence, are applied<sup>6</sup>.
- Ethics provides guidance for analysing why and how structural and social determinants must be placed at

the centre of the integration process. Growing gender and other social inequalities and inequities are driving forces behind HIV and violence against women as two human development and rights problems. Gender discrimination, social exclusion, poverty, and power relations in all levels of society, including between rich and poor countries, play an important role in the ways both problems intersect, as well as their consequences for women. Critical ethics analysis helps conceive of HIV and violence against women as the result of behaviours, but also as resulting from policies, institutional responses, prevailing structures of cultural attitudes and social power.

- Ethical considerations regarding meaningful participation of those most affected by HIV and violence against women are an important concern for integration of HIV and violence against women policies and programmes.
- Ethics and human rights frameworks must be used to ensure that HIV and violence against women services, research and prevention interventions are implemented, guaranteeing access to treatment, care and support of those in need<sup>7</sup>.
- In the case of violence against women, it is vitally important to work from an ethical perspective, given the extreme sensitivity of the issue, the fact that interventions take place in complex situations, and there is a risk of

contributing to prolonging or increasing the effect of violence experienced by women. Taking an ethical perspective in these circumstances is not only one option, but an obligation which makes the difference in situations in which basic ethical principles are compromised in relation to the well-being of people: liberty, autonomy, social justice.

**...ethical reflection also allows us to create better laws, which enable practical interpretations of a series of agreed principles...**

decision-making respects them as human beings and agents of change.

If participation is to ensure that the principle of beneficence is reflected in decision-making, it must be explicitly supported. Women living with HIV have too often been invited to attend policy meetings at short notice and without sufficient time to prepare. There is also a tendency for policy makers to invite the participation of individual women, rather than inviting

**PARTICIPATION AS A CORNERSTONE OF ETHICS**

The participation of women living with HIV, and of communities, is crucial to advancing collective responses to the challenges of HIV and violence against women<sup>9</sup>. The ethical principle of respect for autonomy underlies the principle of participation: involving women living with HIV or those who have experienced violence in policy and programming

women's groups to send a representative. Papers for meetings may be sent by email rather than in hard copy, putting the onus on the women participants to organise and pay for printing of what can often be lengthy documents. There are rarely opportunities for women participants to learn about or observe the meeting culture before taking part, making it difficult to play a full role, and to adapt to the particular way of working of any given meeting or group. Women participants may find they are a lone voice in the meeting, or may feel they are expected to be 'representative' – whether they are or not. Financial resources to cover the costs of participating are not always made available, or are reimbursed after the event, placing an additional burden on women<sup>10</sup>.

*We have worked tirelessly to get our views onto the agenda and represented in decision-making arenas of all types of institutions. However, external agencies often fail to realise the burden on individuals of being asked to speak without adequate support. This can result in exhaustion and difficulties in balancing family and work responsibilities and complicated treatment regimes.<sup>8</sup>*

Women living with HIV and women who experience violence must be at the centre of the response. Women who use

*When it occurs, 'participation' is offered like a treat, a bonus or a meal ticket - an all-expenses paid trip to New York, what more could a (poor, uneducated, marginalised, HIV-infected, female) person ask for? Rarely, if ever, do those creating the policy, holding the meeting, developing the programme, ask: what are your priorities? Where do you think we should start? What are the biggest challenges facing you at home? What do you think this is all about?<sup>11</sup>*

drugs and women sex workers have important insights into the intersections between violence and HIV, and the most effective ways to address these, as do women migrants, indigenous women, women who are deprived of liberty and others who are particularly affected by the social and structural determinants of HIV and violence against women. Their perspectives, contributions and comments must be sought out in line with ethical principles.

However, simply allowing women's participation does not address the issues of poverty, socio-economic status or vulnerability. An ethical approach requires not only that women's participation is permitted, but also that they are provided with the support needed to participate effectively. To this end, it is important that women's organisations are adequately funded and supported.

#### FOOTNOTE:

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# Speak Up!

## Women changing the course of the HIV epidemic

*With members across the country, the U.S. Positive Women's Network has its finger on the pulse of what matters to women living with HIV in the U.S. The past two years, since the last International AIDS Conference, have brought tremendous potential for positive change for U.S. women – the creation of the first U.S. National HIV/AIDS Strategy<sup>1</sup> and the passage of the Patient Protection and Affordable Care Act<sup>2</sup> to name two – especially in the areas we believe are most critical to securing HIV positive women's rights: meaningful involvement of women living with HIV in all aspects of decision-making; ending HIV criminalisation; and securing sexual and reproductive justice, economic justice, prevention justice, and women-centred care.<sup>3</sup>*

### **Naina Khanna, Brook Kelly**

**Y**et, we know that without forceful advocacy by and for women living with HIV some of these advances may not live-up to their promise. With that in mind, the Positive Women's Network has focused on a few key areas for advocacy: the intersection of HIV care and prevention, sexual and reproductive healthcare and gender-based violence; women-controlled prevention tools; and how the implementation of the Affordable Care Act will create opportunities for these.

Current data confirms what so many women living with and affected by HIV know from experience – race, gender, geography and other structural and social variables impact health access, quality of care, and health outcomes for women living with HIV.

*...poverty, intimate partner violence and food insecurity are increasingly recognized as factors significantly associated with increased high-risk sexual behaviors,*

*decreased initiation and retention in care, and worse clinical outcomes.<sup>4</sup>*

Related to these structural factors are societal realities that impact whether or not women living with HIV will seek and attain the care and treatment they need. For example, the establishment of trusting and respectful doctor-patient, and other HIV service provider relationships, and the creation of laws and policies that intentionally or unintentionally discriminate against and negatively impact people living with HIV, can contribute to health outcomes and create barriers for women seeking HIV care and treatment.

President Obama's National HIV/AIDS Strategy (NHAS), released in July 2010, includes three priorities: 1) reducing the number of persons who become infected with HIV annually, 2) increasing access to care and optimising health outcomes for people living with HIV, and 3) reducing HIV-related health disparities.<sup>5</sup> Unfortunately, while the NHAS points to the crisis epidemic among women, especially Black and Latina women

in the U.S., the NHAS implementation and operational plans have no specific goals or targets tied to reducing incidence among women, improving access to, or quality of, care for women, or improving the health outcomes of women living with HIV.<sup>6</sup> In addition, issues that disproportionately impact women, including the need to integrate sexual and reproductive healthcare into HIV care settings, and intimate partner violence receive no attention whatsoever in the National HIV/AIDS Strategy, which, advocates say, is a serious missed opportunity to improve services for women.<sup>7</sup>

**...a close look at gender inequality and the ways in which women's experiences are accounted for in HIV prevention programmes and healthcare systems...**

While President Obama's FY 2013 budget is relatively good in terms of domestic HIV funding overall, the only programme the President targeted for cuts in our HIV safety net – The Ryan White Program – was Ryan White Part D, which is specifically designed to afford ongoing care for women and youth affected by HIV.<sup>8</sup>

Reducing health disparities experienced by women living with HIV requires a close look at gender inequality and the ways in which women's experiences are accounted for in HIV prevention programmes and healthcare systems. A recent editorial in the *Journal of Infectious Diseases* stated

that '[i]dentifying which factors are the most significant barriers to participation in care and designing appropriate interventions are necessary to make any headway in erasing the disparities that are evident in'<sup>9</sup> health outcomes for women living with HIV.

### **SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS AND GENDER-BASED VIOLENCE**

The U.S. Positive Women's Network conducted a survey of over 100 U.S. women living with HIV from February 2010 to January 2011. In the survey, women were asked about their HIV testing experiences, provider attitudes and knowledge about their sexual health and reproductive choices as women living with HIV, and the effects of criminal HIV exposure and transmission laws on their personal decision-making, and on the HIV epidemic overall. An analysis of results from the survey documented in *Diagnosis, Sexuality, Choice*,<sup>10</sup> revealed that the following rights of women living with HIV in the United States are routinely violated.

#### *The right to sexual and reproductive health and reproductive choice*

HIV specialists and general practitioners are not adequately informed about HIV positive women's reproductive rights and options, thereby limiting the full range of reproductive choices and options for women living with HIV.

*The right to be free from harmful HIV-related stigma*

HIV-related stigma and lack of provider professionalism, such as inadequate confidentiality policies, or discriminatory treatment, impacts women's decision-making when it comes to accessing care or making decisions related to their reproductive health and choices.

*The right to accessible and high quality healthcare*

Women often do not know they are at risk of HIV or are not encouraged to get tested for HIV. When receiving HIV positive test results from doctors, women have experienced

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

Lack of information on the part of providers may result in late testing, poor health outcomes, and an inability to provide life-saving referrals to women-centred supportive services.

*The consequences of criminalising HIV positive people's sexuality*

The majority of the respondents felt that laws criminalising HIV transmission and exposure are not an effective HIV prevention

strategy. If anything, many of the respondents cited the harm that could result from such laws. Laws that criminalise

HIV exposure and transmission can be used as tools of abuse, increase the already pervasive stigma faced by women living with HIV, and may contribute to discrimination, as well as hinder testing, disclosure and treatment adherence campaigns.

At a recent meeting of the Presidential Advisory Council on HIV/AIDS (PACHA), national leaders in HIV prevention, care and research spoke eloquently about the HIV crisis among women in the United States, the need to better integrate sexual and reproductive health services with HIV services, and the need to address child sexual abuse and violence against women as key aspects of our national HIV response.<sup>11</sup>

Every single expert – researchers, medical doctors, psychiatrists, trauma experts, women living with HIV, and community-based advocates from entities as diverse as the National Institute for Health (NIH) and Sisterlove, Inc., a women-led community based organisation in Atlanta – keyed in on the relationship between HIV and violence against women as a factor that increases women's vulnerability to acquiring HIV, and that makes women likely to suffer poor health outcomes once diagnosed with HIV.<sup>12</sup>

**...rights of women living with HIV in the United States are routinely violated...**

**...thereby limiting the full range of reproductive choices and options for women living with HIV...**

research study comparing the health outcomes of HIV positive women who had experienced violence (the study group) with HIV positive women who had not (the control group). She could not recruit enough women to form a control group. That is, Dr. Dill was unable to find enough women living with HIV who had not suffered violence in their lives to undertake a scientifically legitimate comparative study.

Although every expert at this national meeting from Alabama to Chicago to Atlanta to Washington, DC, identified addressing violence against women as a major component of the HIV response, the National HIV/AIDS Strategy completely failed to articulate the relationship between HIV and violence

**...laws may contribute to discrimination, as well as hinder testing, disclosure and treatment adherence campaigns...**

Dr. Laurie Dill, Medical Director of Medical AIDS Outreach of Alabama, shared a story from her clinical practice of trying to conduct a

for women. Similarly, the Strategy failed to identify securing sexual health and reproductive rights as pivotal to addressing the HIV epidemic. Additionally, the Strategy did not articulate a single

goal to explicitly reduce new infections among women or to increase HIV positive women's access to quality care (e.g. by ensuring integration of sexual and reproductive healthcare services in HIV care settings). These continued oversights by our government continue despite new data from the HIV Prevention Trial Network's ISIS study that showed rates of HIV incidence among Black women in some geographic hotspots are five times higher than the estimated national average.

**U.S. HEALTHCARE REFORM AND WOMEN**

**LIVING WITH HIV**

In 2010, the Patient Protection and Affordable Care Act (ACA) was passed by our legislatures – the first bill to attempt to reform the U.S. health care system.<sup>13</sup> The bill was immediately challenged by states wishing to overturn key provisions of the legislation. The legal battle reached the U.S. Supreme Court and in January 2012, Women Organized to Respond to Life-threatening Diseases (WORLD) and 16 other organisations led by Lambda Legal filed with the Supreme Court a friend-of-the-court brief in support of the Affordable Care Act (ACA).<sup>14</sup> The Supreme Court began hearing oral arguments in March 2012 and a decision is expected to be reached by June. In the meantime, the U.S., and women in particular who shoulder the greatest burden of our country's healthcare disparities, are waiting to see how the Court will decide the fate of the ACA.

We know that the HIV epidemic thrives on a lack of quality, acceptable, affordable and accessible healthcare.<sup>15</sup> We also know that discrimination in healthcare based on race, ethnicity,

gender and gender identity, pre-existing conditions, and economic status is rampant.<sup>16</sup> No one law can solve all of these problems, in fact the ACA, if upheld, will not extend to recent or undocumented immigrants in the U.S. But the Affordable Care Act is a first and necessary step toward reforming our healthcare system to better meet the needs of all people, and in particular women living with HIV, because it has the potential to address many of the failures of our current system to integrate the key healthcare needs of women, as well as provide non-discriminatory, consistent and more affordable quality care.

The full implementation of healthcare reform is vital to women living with and affected by HIV for a number of reasons:

1. *Healthcare reform will increase access to health insurance by expanding the Medicaid programme to all people who live below 133% of the federal poverty level (FPL) period – disability status will no longer be required<sup>17</sup>*

This will have a hugely positive impact on the health of all people living with HIV, since currently 29% of HIV positive people have no health insurance whatsoever often because they have not become sick enough to be considered disabled for the purposes of Medicaid eligibility.<sup>18</sup>

Removing the cruel disability requirement from Medicaid eligibility for those living below 133% of the FPL is especially important for HIV positive women. Women living with HIV, 76% of whom have children under 18 living in their households, as well as other caretaking responsibilities, cannot

afford for their health to deteriorate in order to qualify for healthcare.<sup>19</sup> Nor should they have to. Removing these barriers and expanding the Medicaid programme is key to reducing the health disparities experienced by so many women living with HIV.

2. *Healthcare reform will bring down healthcare costs for women living with HIV. One in two women report delaying healthcare visits due to costs<sup>20</sup>*

For a woman living with HIV, delaying vital healthcare needs, due to lack of funds and paying out of her pocket for care, can potentially have a devastating impact on her well-being and her financial security.<sup>21</sup>

Healthcare reform will bring down healthcare costs for women by requiring

insurance companies, as well as Medicaid, to cap out-of-pocket expenses, and ban insurance companies from dropping women from coverage when they get sick.

3. *Healthcare reform will prohibit health insurance discrimination against women and against people with pre-existing conditions, including HIV<sup>22</sup>*

Currently, women face shocking levels of discrimination in healthcare coverage. A 22-year-old woman can be charged

**...that makes women likely to suffer poor health outcomes once diagnosed with HIV...**

**...the HIV epidemic thrives on a lack of quality, acceptable, affordable and accessible healthcare...**

are considered pre-existing medical conditions, as is a history of intimate partner violence.<sup>24</sup> Under the current practice, women living with HIV can be denied health insurance solely as a result of their HIV status, forcing many to cobble together healthcare coverage from different sources such as ADAP, Medicaid, and Medicare. Navigating these programmes can be time-consuming and difficult. Taking care of one's health should not be a full time job! Getting medications covered requires women to live below a certain income level – in many cases, well under the poverty line.

The Act already prohibits discrimination against children for pre-existing conditions and in 2014 will prohibit sex and health status discrimination against all people.<sup>25</sup> These protections will be a long overdue fulfilment of HIV positive women's human rights.

**4. Healthcare reform will provide greater healthcare security**

Less than 50% of women have the option of obtaining health insurance through a job and when jobs change, health coverage

insurance premiums is often lost or 150% times higher than a 22-year-old man with a similar health history.<sup>23</sup> Pregnancy and history of previous pregnancy

is often lost or broken.<sup>26</sup> Studies have shown the importance of building trusting and long-lasting relationships with HIV medical providers.

Women cannot afford to take breaks from medications, as a result of a lack of coverage or

unaffordable co-pays. Reliable, continuous health coverage with a trusted provider is essential for women living with HIV. Spotty insurance coverage makes this impossible.

Through the creation of state-based health insurance exchanges, the ACA will ensure that more women have dependable and continuous uninterrupted coverage for themselves and their families regardless of their employment status.

**5. Healthcare reform will create a health care system that better meets women's unique needs**

Currently, women are at the mercy of their health insurance provider for many essential and life-saving prevention services.

With the implementation of the ACA, several basic and necessary services will be offered and covered by all healthcare

**...the potential to address many of the failures of our current system to integrate the key healthcare needs of women, as well as provide non-discriminatory, consistent and more affordable quality care...**

plans for free.<sup>27</sup> Some of these critical services include Well Women Visits that cover prenatal and postnatal counselling and care; HIV and STI testing and counselling; human papilloma virus testing; breastfeeding support, supplies, and counselling; and screening and counselling for domestic violence. That means these services will be offered to all women without being charged for co-pays and/or deductables!

The provision of these prevention services, free of cost, means a phenomenal healthcare win for all women, especially women living with HIV. As we know, gender-based violence

**...key to reducing the health disparities experienced by so many women living with HIV...**

contributes to women's vulnerability to HIV and hampers the wellness of women living with HIV. The fact that the ACA recognises the far-reaching

nature of violence in women's lives by insisting that intimate partner violence screening and counselling be a free service is an extremely important step in coming to terms with what our Attorney General Eric Holder admits as a 'staggering' amount of intimate partner violence experienced by women.

Moreover, these prevention services for women can begin to address some of the discrimination women living with HIV face in exercising their reproductive options.<sup>28</sup> Women living with HIV are often not offered sexual and reproductive healthcare

services, such as prenatal counselling, STI testing, or human papilloma virus (HPV) testing, because doctors assume that people's sex lives end with an HIV positive diagnosis. We know this is not true. Many women living with HIV have happy and healthy sex lives, and need these types of reproductive health services as much, if not more, than other women in order to stay healthy.

The Affordable Care Act is a unique opportunity to reform our healthcare delivery system. It lowers costs for insurance, prohibits gender and health status discrimination, provides continuous healthcare coverage, and prioritises women by fully covering our key healthcare needs. It would be a national tragedy if the Supreme Court finds the bill to be unconstitutional because it requires all people to be insured. Expanding coverage to everyone should be our national goal, not our fear.

**THE IMPORTANCE OF COLLECTIVE ADVOCACY – THE ESTABLISHMENT OF A WHITE HOUSE WORKING GROUP ON THE INTERSECTION OF HIV/AIDS, VIOLENCE AGAINST WOMEN AND GIRLS, AND GENDER-RELATED HEALTH DISPARITIES**

In response to opportunities to improve the lives of women through the implementation of new U.S. policies, like the Affordable Care Act or National HIV/AIDS Strategy, and the propensity for women, especially women living with HIV, to be left out of the decision-making process, or included as an

afterthought, the PWN helped to found the *30 for 30 Campaign* in April 2011. The *30 for 30 Campaign* serves as a coordinating body of HIV and reproductive health organisations from every region of the country working to ensure that the unique needs of women, including transgender women, with regard to HIV prevention, care and treatment are addressed in all relevant funding, programmes and policies. The *Campaign* is especially committed to alleviating HIV-related health disparities for women of colour who currently make up more than 80% of HIV cases among women in the United States.

The Campaign has had unprecedented success in moving a women's agenda in the HIV response, due to the diversity and commitment of coalition partners. With the three priority areas, the Positive Women's Network, and other member organisations, have been able to leverage collective energy to make waves in U.S. AIDS policy to 1) expand and expedite the provision of facilitative support services and housing services for women living with and affected by HIV;

**...women are at the mercy of their health insurance provider for many essential and life-saving prevention services...**

and readily available by integrating the provision of the three healthcare delivery areas of greatest importance to women: (a) HIV prevention, treatment and care; (b) sexual and reproductive health

services; and (c) intimate partner violence prevention and counselling; and 3) produce better data and more targeted research to identify and address women's needs. All data must be disaggregated by sex and gender.

Women-controlled prevention tools must be developed and made available.

A recent and major accomplishment of our collective pressure has been President Obama's establishment of the White House Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-related Health Disparities.<sup>29</sup> The intersectional Working Group differs significantly from the siloed approach to women's health that the U.S. has historically taken. The Working Group has a broad charge and incorporates a human rights-based affirmative approach to addressing the HIV epidemic for women, including coordination of U.S. agency efforts, to 1) raise governmental and public awareness about the need to address the intersections of HIV, violence, and gender-based health disparities; 2) to integrate sexual and reproductive health services, gender-based violence services, and HIV services; 3) promote better research into

**...the provision of these prevention services, free of cost, mean a phenomenal healthcare win for all women, especially women living with HIV...**

the factors that create gender-related health disparities; and 4) incorporate specific, evidence-based goals addressing HIV among women, including HIV-related health disparities among women of colour in the National HIV/AIDS Strategy Implementation Plan.<sup>30</sup>

The White House Working Group has the potential to be a powerful governmental body by providing a space for forethought and coordination in the implementation of policy impacting women in multiple facets of our lives. Yet to date, the formation of the Working Group has garnered little to no media attention, and as of the time of this writing it remains to be seen what power it will have to actually shift policy. It is PWN's hope that the 2012 International AIDS Conference will bring some bold announcements, including amendments to the National HIV/AIDS Strategy, that explicitly address the needs of women living with and vulnerable to HIV.

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# The common mindset...

## Gender inequality and its effect on HIV testing and disclosure

**Sierra Mead**

*South Africa offers a model of seemingly endless proof that violence increases women's risk of HIV. Research suggests that women's economic dependence, coupled with male abuse of women, compromises their ability to insist on safer sexual practices in relationships<sup>1</sup>, thereby placing them at higher risk of HIV transmission.*

### INTRODUCTION

**C**oupled with various statistical data suggesting that violent and controlling men engage more often in risky sexual practices and, therefore, are more likely to have STI's,<sup>2</sup> there is little doubt that violence is linked to HIV transmission in regards to South African women. Furthermore, there is an assessment that has received less attention and deliberation, but is equally as critical to the discussion of HIV transmission: the real risk of violence as a response of HIV status disclosure.

There are many barriers that restrict South Africans, especially South African women, from learning their HIV status through voluntary testing. There are the classic risks of stigma, discrimination and gossip, isolation from friends and family, and/or rejection on social, professional, and economic levels.

While these are certainly serious problems with the current social climate, they also pose a problem to the prevention of HIV, because few people are inclined to submit to these risks and get tested for HIV. There is a less spoken peril facing South African women who avoid HIV testing and disclosure for fear of a violent reaction from their partner and/or families.

Because of South Africa's firm cultural elevation of patriarchy, women are perceived as inferior to men and also are generally socially and economically dependent on them. Due to South African males' practice of exerting perpetual domination over women in society, women receive less education, endure harassment, rely on men economically, and are at higher risks for acquiring HIV, because women are least in the position to demand and dictate their sexual rights. The patriarchy in society has such a firm grasp on women that fear of intimate partner violence can lead to women not getting tested for HIV, which not only puts them at risk, but violates their fundamental human right to participate in any decision affecting their personal health.<sup>3</sup>

HIV testing is a 'tool' that could hypothetically reduce the transmission of HIV because, among other things, it increases people's knowledge and awareness of their status and helps direct those with positive tests to antiretroviral therapy; however there are too many barriers blocking South Africans from getting tested for the potential of HIV testing to become a reality.

**...few people are inclined to submit to these risks and get tested for HIV...**

Because of gender inequality, broaching the subject of HIV testing in a culture that customarily refuses to discuss sex could result in emotional,

**PATRIARCHY IN SOUTH AFRICA**

The medley of ethnicities in South Africa differ from one another in various ways. However, whether the culture's roots are Afrocentric or Eurocentric, they are all deeply influenced by one common institution: *Patriarchy*. Today, South African women of every sector of society and cultures are experiencing an uneven power relationship with the men in their family and community, as well as in economic, and social settings.

psychological, and/or physical violence. Women automatically fear their partner's reaction to the discussion or to the disclosure of their positive status, creating a barrier and reason not to participate in HIV testing. Generally, both men and women in South Africa view the initiation of HIV testing as a woman's responsibility, because she attends the clinic and is, to a certain extent, responsible for family planning.

Patriarchy was once the '*cherished*' and '*honourable*' social belief that the father is the leader and protector of the family circle, but has developed into an absolute norm, value, and institution of paramount importance in society, where a father's leadership is dominant and is

HIV testing and taking responsibility to initiate discussion of HIV testing in a household should not rest solely on the women. Both men and women need to become more comfortable with communication about sex, condom usage, and HIV testing. However, this cannot be accomplished until the groundwork is laid and men are of equal economic, social, and professional status to women. Because of the deep roots of patriarchy in South African society, this mindset shift would alter the deeply bound philosophy and actual reality of gender inequality burnt into the minds of the youth at a young age. Until gender inequalities are overcome, it is likely women will live in fear of violence as a reaction to their HIV status disclosure, as well as fear to get tested for HIV.

extended from merely the spheres of the family to all realms of society and social intercourse.<sup>4</sup>

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Correlating with the development of the male into a dominant figure of society is the shift of women's position of inferiority to men. With what started as a conception that the male must protect his family, and, therefore his wife and daughters, has expanded, justified by sexism, into the seemingly social acceptance that women are '*intellectually inferior to men and consequently not suitable for positions of management, in the spheres of education, and elsewhere*'.<sup>5</sup>

Because of this conclusion, South African women are  
*...kept in their position of subservience through measures such as less educational opportunities than men, economic dependence, physical harassment, exclusion from leading roles in education, politics, the church and society at large.*<sup>6</sup>

Subsequently, women have come to accept their inferior position in society as a 'natural' and 'irreversible' aspect of life.

Indeed, patriarchy has become such a normal part of life in South Africa, that it is hardly recognised as a harmful influence in society. Traditional practices, like polygamy, encourage gender inequality; there is a greater expectation and acceptance of men to have multiple partners, because of the cultural mindset that men biologically need more sex than women.<sup>7</sup> Zulu and Xhosa cultures, for instance, celebrate men with multi-sexual partnerships, rationalising that it validates one's manhood, and even have two complementary terms for such men: *isoka* (playboy) and *amakrwala* (initiated men).<sup>8</sup> These terms, intentional or not, glamorise gender inequality. Feminist writer and academic Pumla Dineo Gqola explains that,

*...sex with multiple partners is so entrenched in South Africa that it is a religion, a basic moral philosophy for most people here. It is often simply called culture or, specifically, African culture. Political leaders who*

*marry an increasing number of wives and royalty that flaunts an equal number of wives and concubines are highly visible.*<sup>9</sup>

South Africa has one of the world's most democratic constitutions, and while it is true women have gained substantial rights *on paper*, gender inequality is prevalent in reality. 'Many men believe they are the custodians of African culture and regard women as inferior, and believe that women should obey men',<sup>10</sup> which, in turn, leads to the justification of gender-based violence and intimate partner violence. In some ethnic spheres, women are still viewed as chattel owned by their father and eventually as the property of their husbands; therefore society requires women

to obey the men's commands and condones violent punishment or sexual abuse for 'misbehaviour' or failure to obey the male's rule.<sup>11</sup>

When distinguishing the reasons behind gender-based violence and intimate partner violence as an outcome of disclosure of HIV status, patriarchy and the gender inequality that ensues are not even the underlying problems. The common mindset that the perpetual state of gender inequality, economic reliance on men, social discrimination, and gender-based abuse cannot be altered or improved is, in actuality, what impedes any progress made to improve women's standing in society or the removal of barriers to HIV testing.

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Former Constitutional Court Justice Abie Sachs outlines the challenge that the nature of sexism and patriarchy's complex historical roots pose in the response to gender barriers. Justice Sachs reflects that

*...Indeed, [patriarchy] it is so firmly rooted that it is frequently given a cultural halo and identified with the customs and personality of different communities. Thus, to challenge patriarchy, to dispute the idea that men should be the dominant figures in the family and society, is seen not to be fighting against male privilege but as attempting to destroy African tradition or subvert Afrikaner ideals or undermine civilised and decent British values.<sup>12</sup>*

With the expectation of male dominance in every aspect of society comes the warped portrayal of manhood perpetuated by the expectation of gender roles in sexual relationships and activities.

**MALE DOMINANCE AND ITS CORRELATION WITH HIV**

Gender is statistically related with the spread of HIV; the gender gap in people between the ages 20-24 in South Africa who are living with HIV is wide. An alarming 24.5% of women (20-24 years) are living with HIV, as compared to 7.6% of men in the same age group.<sup>13</sup> Intimate partner violence is also correlated with the high percentage of women living with HIV, and a 2011

study discovered that young men (under 25 years) who had been physically violent towards a female partner have twice the chance of acquiring HIV, as men of that age who had not been violent.<sup>14</sup> HIV prevalence is significantly higher in men who are repeatedly violent towards their partner, and there is substantial evidence that a woman's exposure to violence increases her risk of being infected with HIV. The construction of values and beliefs that surround masculinity is tied to gender dominance in sexual relationships and inhibit women's basic right to protection.

Because of the patriarchal society, women are usually subjected to violence as a result of their perceived 'misbehaviour' and non-conformity to how a woman is socially and culturally expected to behave. Women generally do not possess the ability to negotiate abstinence or condom use, and are fearful or embarrassed to discuss sex with their partners.<sup>15</sup>

**HIV TESTING**

Eighty percent of people living with HIV do not know their positive status. Testing for HIV is an important factor in

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**...the common mindset ... is, in actuality, what impedes any progress made to improve women's standing in society or the removal of barriers to HIV testing...**

the ultimate decrease of HIV transmission. HIV testing is a 'tool' that potentially enables people to cope with the anxiety associated with the uncertainty of not knowing, promotes safer sex, and empowers individuals to protect themselves from the risk of HIV transmission. The early detection of HIV may also improve medical and psychological support for people living with and vulnerable to the virus. Research has shown that HIV testing can reduce high-risk sexual practices and can decrease rates of sexually transmitted infections.<sup>16</sup> Those who get tested can be directed to adequate treatment of ART, AZT, or HAART. In reality, however, studies show that only one in five South Africans, who know about HIV testing, have been tested for HIV.<sup>17</sup>

Stigmatism associated with HIV testing is enough for most people to avoid HIV testing, but for women, there is the added element of gender inequality and potential risk that testing and disclosure of their status to their partner will result in the loss of economic support, blame, abandonment, physical and/or emotional abuse, and/or disruption of family relations.<sup>18</sup> Although it is clearly stated in the *National Health Act* of 2003, Section 8(1), that: *A person has the right to participate in any decision affecting her/his personal health and treatment*,<sup>19</sup> often times women, especially pregnant women, get pressured by nurses and society to get tested, even if they are not prepared for the ramifications. On the other hand, there are cases when women avoid

clinics all together for fear of being coerced into getting tested, and eventually having to disclose a positive status to their partner.<sup>20</sup>

Because women are most likely to attend clinics, and therefore more likely to get tested or be coerced into getting tested, both men and women have come to the conclusion that HIV testing is 'a woman's job'. In 2010, the NIMH (National Institute of Mental Health) Project conducted a study that examined South African women and men negotiating HIV risk and relationship intimacy. The NIMH report finds that, '*both men and women usually reported that it was the female partner who was expected to initiate discussions*'.<sup>21</sup>

Because of the patriarchal prevalence, it seems women have no choice but to accept responsibility to initiate discussions of HIV and seek healthcare services. Is it not ironic that the ideal of patriarchy originated from the social belief that the father is the leader and protector of the family circle? But, unfortunately, that fundamental title does not apply when it comes to the uncomfortable, difficult, and emotional task of confronting the reality of HIV. That is a challenge for the women to overcome.

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when they try to practice  
their basic rights...**

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services...**

A 25-year-old female in the study stated:

*It is not easy for a male person to think that they need to test because commonly males do not really care that much about [testing]. The problem [of testing] is with us females.<sup>22</sup>*

However, as mentioned above, as a result of gender inequality, women do not possess the ability to negotiate abstinence or condom use, and are fearful or

**...it is unrealistic to expect women, who are stripped of their sexual rights, to comfortably initiate a discussion with their partner about HIV and HIV testing...**

embarrassed to discuss sex with their partners, so it is unrealistic to expect women, who are stripped of their sexual rights, to comfortably initiate a discussion with their partner about HIV and HIV testing. Despite the expectation for women to initiate discussions on HIV, the study comments that women ‘generally reported an inability to persuade a reluctant or defiant partner to test’, and the man relied on the female partners’ status to determine his own.<sup>23</sup> It has been proven that women who are tested in greater numbers than men and with limited support, are vulnerable to stigma, discrimination, abandonment and violence.<sup>24</sup> Men’s lack of involvement in family planning, as well as their perpetual intimidation of

women, has resulted in a lack of perceived responsibility for controlling reproduction and STIs.<sup>25</sup>

### **VIOLENCE AS A RESULT OF HIV DISCLOSURE**

There are studies conducted in South Africa that highlight the fear of violence at disclosure and show that women are at risk of negative outcomes when disclosing their HIV status to male partners. However, it might not be clear how the post-disclosure violence compares to the level of violence in the relationship before disclosure.

The World Health Organization (WHO) conducted a study in sub-Saharan Africa that focused on intimate partner violence and HIV. The study subsequently addresses violence as a result of disclosure to one’s sexual partner and found that:

*...women were afraid to ask for money or permission from their husbands to attend HIV/AIDS facilities or seek information and in some cases explicitly forbidden from taking HIV tests.<sup>26</sup>*

The study shows 16-51% of women from Tanzania, South Africa and Kenya did not disclose their HIV status to their partner for fear of violence.

A study done by Amnesty International in 2008 in the Mpumalanga and KwaZulu Natal provinces of South Africa reveals similar findings where, because the woman’s partner is in denial about his own HIV status, he resents that she goes to the clinic; some women experienced abuse or active prevention by partners when they tried to access health services or medication.<sup>27</sup> In the situations of intimate partner violence,

the study reports that:

*...very few of the women...who had gone to a clinic seeking medical care for injuries or advice about domestic violence had been referred on to support services or a shelter by the clinic.*<sup>28</sup>

Not only are women at risk of abuse when they try to practice their basic rights, they also do not have a proper support system or counselling platform to manage their predicament. The Amnesty International study found that in this environment of gender-based inequality, women experience harassment or violence when they test positive and wish to disclose their status.<sup>29</sup>

**CONCLUSION**

In the attempt to reduce HIV transmission, voluntary disclosure has been identified as an important factor, because its ramifications, amongst other things, potentially lead to safer sex practice and guide both men and women to adequate and timely treatment and services. In order to address the barriers

**...women experience harassment or violence when they test positive and wish to disclose their status...**

that hinder people from getting tested for HIV, the public needs to modify its outlook on HIV stereotypes and stigma to provide support for both women and men with HIV. Addressing

the effectiveness of post-test counselling services for people with HIV, as well as administering educational services to the general public would improve the current attitude adopted by many South Africans towards HIV.

South Africa's National Strategic Plan<sup>30</sup> addresses the challenges of HIV risks, and maps out the government's steps that will be taken towards reducing new HIV infections and discrimination. The NSP recognises the need for education, improved access to information and legal remedies to

*...reduce vulnerabilities and remove structural barriers to accessing services: promote gender equality and remove harmful gender norms.*<sup>31</sup>

Increased awareness and education will help reduce HIV-related stigma and discrimination, and additional skills training and educational programmes for women will, hopefully, reduce their economic dependence on men. HIV testing services should begin to anticipate and address the possible consequences of violence for women disclosing their positive HIV status to their partner; it is important for these services to include skills and capacity assisting women with the process of disclosure. These changes can be initiated, as they are mechanical modifications, and can be made by improving government standards and systems. Violence as a result of

**...women at risk of abuse when they try to practice their basic rights...**

disclosure, however, is a more challenging problem to address because, as explained above, the violence is a product of the deeply rooted cultural institutions of patriarchy and perpetual gender inequality.

The greatest challenge is changing the powerful social attitude that embraces gender inequality to the extent where most South Africans cannot imagine a life without it. To reiterate former Constitutional Court Justice Abie Sachs:

...to challenge patriarchy...is seen not to be fighting against male privilege but as attempting to destroy African tradition or subvert Afrikaner ideals or undermine civilised and decent British values.<sup>32</sup>

Until mindsets shift and women no longer face gender inequality, women will continue to avoid getting tested for HIV, because the fear of living with HIV and not knowing, outweighs the possible risks and consequences of abandonment, rejection, discrimination, loss of economic stability, and/or violence as a result of HIV status disclosure.

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# Positive and pregnant... how dare you<sup>1</sup>

## Access to reproductive and maternal healthcare for women living with HIV in Asia

*The scaling-up of testing of pregnant women in order to prevent vertical transmission of HIV from mother to child during pregnancy and breastfeeding has led to pregnant women living with HIV facing stigma and discrimination, including poor quality care or refusal of antenatal care and delivery services, and increased coercion to be sterilised.*

**Susan Paxton**

**W**ithin this context, the Women's Programme of the Asia Pacific Network of People Living with HIV conducted in 2011 a study on positive women's experiences of accessing reproductive and maternal health services in six Asian countries.

The study used quantitative and qualitative methods: a survey among 757 women (Bangladesh 33, Cambodia 200, India 172, Indonesia 109, Nepal 40, and Vietnam 203), as well as 17 interviews and 10 focus group discussions. Two women living with HIV from each of the study countries were trained as data collectors.

### STUDY SAMPLE

Women who participated in the study were all living with HIV, over 16 years old, and had been pregnant within the past 18 months. Convenience sampling was carried out using networks of people living with HIV. Most respondents were members of a network (Bangladesh 97%, Cambodia 40%, India 43%, Indonesia 35%, Nepal 100%, Vietnam 60%).

The average respondent was 30 years old (range: 17-47 years), and had at least one existing child. Most women had either primary or secondary school education (71%); 57% lived in urban settings and 53% in rural. Overall, 77%

were married or living with a partner, 21% were widows or no longer with a partner, and 2% had never married or lived with a partner. About half (53%) were dependent on their families for income. Respondents had been diagnosed with HIV for a mean of 3.6 years (range: 0-18 years). The majority (56%) were diagnosed prior to their most recent pregnancy, 27% during pregnancy and 10% after delivery. Cambodia recorded the highest percentage of women who knew their HIV status prior to their recent pregnancy (83%); in India, a majority (73%) was diagnosed during pregnancy.

### KEY FINDINGS

#### Counselling

Although the vast majority of women received pre- and post-test counselling, in India, only 50% of women who tested during pregnancy received pre-test counselling, and overall only 9% of women who said the test was not voluntary received post-test counselling. Some women were unaware of being tested for HIV when the test was done, and results were often given to family members. Indian women reported that pre-test counselling often was more persuasion to be tested, than actual counselling.

Some women were given no hope on diagnosis. A doctor told one woman, 'get ready because you are going to be dead soon'. Many women were given misinformation by doctors:

**...pre-test counselling often was more persuasion to be tested, than actual counselling...**

one was told that the risk of her baby getting HIV was 60%; another that if she and her partner did not have safe sex there is a risk of transmission of HIV to the baby; another

woman was told to take paracetamol daily for a year.

The importance of counselling provided by women living with HIV, covering a range of issues and available on a long-term basis, was a recurring theme in interviews and focus group discussions. Women said peers understand their issues and help them open up and ask questions.

*When I received the news I was despairing but then I was referred to [the peer support organisation] and I received peer counselling and I saw other positive women who gave birth to a negative child and then I became hopeful.*  
[Nasrin, Bangladesh]

**Disclosure**

Over 90% of women had told their husband or partner about their HIV status and about half had also disclosed to female family members. In India, disclosure to family was often made by health personnel without the consent of the woman. Many women faced discrimination as a result of disclosure, particularly from in-laws.

*They beat me and treated me very badly and used loose words on my character throughout the neighbourhood. They told everybody I had HIV then tried to force my husband to abandon me.* [Rashma, India]

Some women did not reveal their HIV status to their gynaecologist for fear of discrimination. In Cambodia, incentives, such as free doctor's visits or free delivery are offered to encourage women to disclose in order for them to receive appropriate treatment, but many women choose to pay the extra costs, because they are afraid of the stigma they may face otherwise.

**Antiretrovirals**

The majority of women (64%) were taking ARVs, with 50% initiating them before their current pregnancy; 29% of respondents were on a regimen that included Stavudine (d4T), no longer recommended by WHO. Women suggested continued use of d4T is because government health departments have lots in stock.

Most women not on ARVs said their CD4 cell count was high, yet only 4% initiated ARVs at CD4 counts greater than 350 and the majority did not start until their count was below 200. Only in Cambodia are women starting ARVs once their CD4 count drops below 350. Some women have never had a CD4 count or discussed ARVs with their doctor. Some women stopped ARVs during pregnancy, because of adverse side effects.

**Contraception**

Condoms were the most preferred contraceptive method (64%), but are not used consistently, because partners object to

**...many women faced discrimination as a result of disclosure, particularly from in-laws...**

them, find them inconvenient or cannot afford them.

*When the doctor provides counselling on pregnancy prevention they should also provide counselling to men because it's men who want to have the babies. Most women who have a pregnancy don't want it. It's the men.*

[Semlay, Cambodia]

Condoms are usually the only contraception promoted among women living with HIV, whereas they need methods that they can control – IUDs, pills, injectables or female condoms.

**...whereas if she had told them she had HIV, they would not have done the procedure...**

Opportunities for counselling on family planning were few, as doctors often discourage discussion about sexual or reproductive health.

### **Pregnancy**

Of the 573 women who were no longer pregnant at the time of the survey, 72% had live births and 22% had an abortion, and 6% miscarried or had still births. Overall, 37% of women reported their recent pregnancy was unwanted (Bangladesh 33%, Cambodia 44%, India 10%, Indonesia 33%, Nepal 48%, Vietnam 53%).

Less than half of respondents (45%) said decisions regarding their pregnancy were made together with their partner, 21% said their husband alone makes these decisions, and 11% said they alone make them. Indonesia, Nepal and Vietnam had substantially more women as sole decision makers (range: 13-19%) compared to Bangladesh, Cambodia and India

(range 3-6%). Overall, 9% said their mother or mother-in-law was also involved in decisions around pregnancy.

*My husband and my mother-in-law make all the decisions. I'm usually not consulted. I have many concerns and questions in my heart, but I have never discussed them with anyone, not even my husband or the counsellor.*

[Pragya, India]

*My mother-in-law said she needs at least one grandson. I didn't want to get pregnant once I knew my status, but she didn't know my status and she pressurised me to have a child. She told my husband to find another woman to marry if I didn't get pregnant... When I was six months pregnant I had an ultrasound to determine the sex of the baby and when we knew it was a boy I went ahead and gave birth. [Sunita, Nepal]*

Few women were able to find supportive healthcare workers during their pregnancy.

*When I went to the obstetrics department the staff were afraid of me and said, 'How dare you have a baby. Aren't you afraid to die?' The doctor said, 'You are already positive so your health is not good so you should have an abortion'. He gave me many reasons why I should not continue with the pregnancy. I said to the doctor that I have a right to have a baby under the law.*

[Kieu, Vietnam]

### **Abortion**

Overall, 125 of the women no longer pregnant (22%) reported they had an abortion (Bangladesh and India <1%,

Indonesia 8%, Cambodia 12%, Nepal 25%, Vietnam 44%). Most occurred specifically because of the woman's HIV status; 29% of women who had an abortion said the pregnancy had been wanted.

Many women who were urged to have an abortion faced considerable discrimination when they went for the procedure.

**...many rural women come to the capital for maternal health services, because they are guaranteed confidentiality...**

One woman said staff tried to refer her to a specialist hospital saying that they did not have the right equipment and she had to bribe them to have an abortion.

Another woman went to a private clinic and said she had hepatitis. She was charged more for 'preventive materials and expensive chemicals to sterilise the instruments', but did not face discrimination, whereas if she had told them she had HIV, they would not have done the procedure.

*When I went for the abortion, I had to wait for all the negative women to go first. They used three pairs of gloves and covered all their body with plastic, like a raincoat, and they wore glasses because they were afraid.*

[Hong, Vietnam]

#### **Delivery**

Overall, 37% of the 426 deliveries were via caesarean (Cambodia 7%, India 21%, Nepal 33%, Vietnam 41%, Bangladesh 54%, Indonesia 67%). Many women said they were

not given a choice to have a vaginal delivery. Women recounted extreme instances of discrimination at the time of the delivery, including neglect and abuse by staff and staff refusing to touch them or bathe their newborn infant. One woman's mother was made to wash the blood off the floor after the delivery.

*During the delivery of my baby the doctor wanted to put on two sets of gloves. He had put up on one set of gloves but the baby was already coming out and the doctor tried to push it back in so he could put on another set of gloves.*

[Saru, Nepal]

*I was told to lay down with my feet up [in stirrups]. I was left alone for hours in labour like that, and nobody came to check on me. The first baby came out and fell directly into the rubbish bin under my feet. I could not do anything because the second baby was coming out so quickly. When someone finally came to check on me, the first baby was all black and blue, and dead, and the second one was halfway out. They did not want to touch the baby because they did not want to touch my blood.*

*I heard the second baby cry. He was a real person. But they took him away before I could properly see him and put him on oxygen for five hours, and then told me that he died... I think my babies would have lived if they had gotten proper treatment but I didn't say anything because I didn't want to hear more harsh words directed at me.*

[Navi, Cambodia]

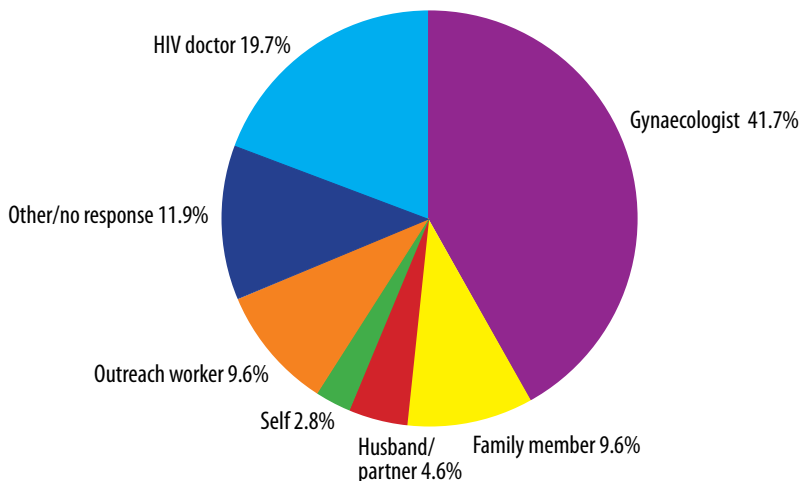
#### **Sterilisation**

Overall, 30% of women were encouraged to consider sterilisation. There was a positive correlation between women

who had caesareans and women who were recommended sterilisation. The majority of recommendations (61%) came from gynaecologists and HIV clinicians and were made on the basis of the woman's HIV positive status.

In some cases, women did not know whether they had been sterilised during their caesarean. Several women indicated they do not have the power to refuse or accept sterilisation, because their health decisions are made by their husbands or family members, or the hospital required spousal consent. In some localities, while the choice was left to the woman, incentives were offered, such as free formula.

**Figure 1: Persons who made recommendation to undergo sterilisation**



*I had a caesarean because my baby was very big, four Kg. They gave me an injection and then only five minutes before the operation the doctor asked me, 'Do you want to do sterilisation?'. [Sophal, Cambodia]*

*They had to give me a C-section because my baby was two weeks overdue but I had to sign a paper agreeing to a*

*tubal ligation as well. I wanted to have another child but I had no choice. [Mai, Vietnam]*

### Maternal health services

Most women (80%) received some pregnancy-related healthcare, 12% did not receive any services despite seeking them and 6% did not seek services. Costs, of transport, doctor's fees and laboratory tests, are major factors for many women in utilising healthcare during pregnancy. In Indonesia, unmarried pregnant women are ineligible for government health insurance.

One Indonesian woman said it costs her one eighth of her monthly income to travel to the hospital. A Cambodian woman said that with the money it costs to get to the clinic, she can feed her family. Many rural women come to the capital for maternal health services, because they are guaranteed confidentiality. Many women borrow money to make the trip.

Satisfaction with services ranged from India 78%, Cambodia 68%, Nepal 68%, Bangladesh 67%, Indonesia 60%, to Vietnam 34%. Overall 42% of women had difficulty finding a gynaecologist to care for them during their pregnancy, and 18% were not satisfied with the confidentiality afforded them. Only 29% of women have had a pap smear. Where services are not integrated, women are shunted between infectious diseases and reproductive health services, which cost extra time and money. Most women believe confidentiality could be better maintained in an integrated healthcare setting.

Several women spoke of discrimination from healthcare

workers. Some nursing staff ask questions such as, ‘How did you get HIV?’ and ‘Why did you get pregnant?’ in front of other patients.

*We are offered the same services as negative women, but we are treated differently. The healthcare worker won't sit on the same chair that I have sat on or use the same pen. When they look into my mouth to examine my throat they stand far away and won't touch me. [Chau, Vietnam]*

*Most nurses at the government hospitals behave badly towards HIV-positive women. They ignore us, and make us wait a long time to see the doctor. The HIV doctors are much better. [Lani, Indonesia]*

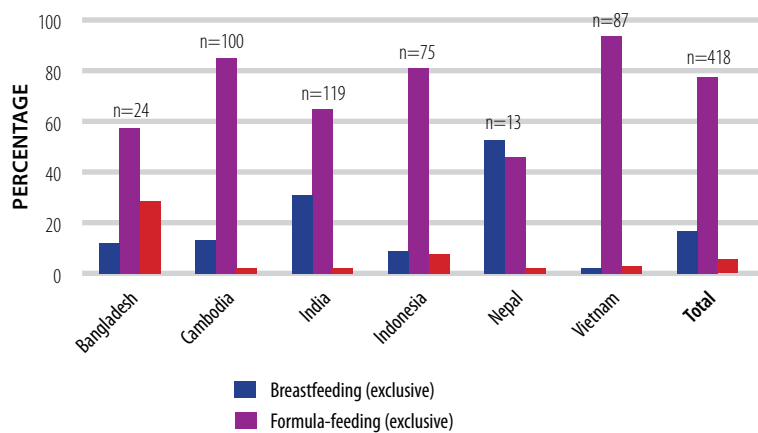
Women repeatedly said that they just want to be treated like normal people.

**Infant healthcare**

Formula feeding was most commonly practiced, except in Nepal. In Cambodia, new Ministry of Health guidelines recommend breastfeeding, in line with revised WHO Guidelines, which recommend breastfeeding as a

good option for all babies, including those born to positive mothers,<sup>2</sup> but many women are afraid to breastfeed, even if they are on ARVs.

**Figure 2: Infant feeding practices, by country**



*They took [my son] away and I didn't see him for two days until I was discharged from the hospital. By then he had already been given formula, so there was no choice to breastfeed. [Lani, Indonesia]*

Of concern, where formula food is not provided, is its cost. Some women go without food in order to buy formula. Sometimes they give their baby sugar water.

*I did not have any formula and my baby was crying all night from an empty stomach so the next day my husband sold my mobile for formula. I felt guilty that I had brought the child into the world and I cannot feed her. [Nasima, Bangladesh]*

Of the 89 infants who were breastfed, only 35% were on

ARV prophylaxis, most from Cambodia and India where ARV drops were available. Over half the respondents (55%) said ARVs were available to their infant (Cambodia 73%, Indonesia 62%, India 48%, Vietnam 44%, Nepal 40%, Bangladesh 36%), but at times access was difficult.

*The hospital prescribed the medicine and gave us the names of four medical stores but they were all out of stock. The government hospital gives first priority to babies born at their hospital and refused to sell to us because we delivered at a different hospital. We finally found the syrup at a private medical store far from our home. [Mena, India]*

*They gave my son AZT while he was in the hospital, and then I continued to give it to him every six hours until he was six weeks old. Then I had no more medicine and it was too expensive to buy. I have not taken him back to see a paediatrician. I am afraid he is also HIV-positive and that it is too late... Also, I cannot afford the HIV test for him. [Riri, Indonesia]*

Infants are often prescribed co-trimoxazole after birth but mothers do not receive adequate information about why this is important, and many worry that the medicine will harm their infant.

## CURRENT CHALLENGES

### Government obligations

As governments move to reduce HIV infections among newborn infants, care must be taken to uphold the rights of women living with HIV. While many countries have

successful programmes to prevent vertical HIV transmission to infants, strategies to prevent unwanted pregnancies among positive women have largely been forgotten, and family planning needs among women living with HIV remain high.

All countries involved in this study have signed and ratified the Convention on the Elimination of Discrimination Against Women (CEDAW), which affirms women's rights on an equal basis with men, including the right to decide freely and responsibly on the number and spacing of their children. Governments have an obligation to provide women living with HIV with a standard of healthcare equal to that provided to HIV negative or untested women.

Healthcare providers do not consider contraceptive options other than condoms among positive women. Counselling is targeted towards the women, but they have as little control as negative women over condom use, so unwanted pregnancies are common. Positive women are discouraged from pregnancy, and many do not want to become pregnant, but they are given no realistic means to avoid unwanted pregnancies.

Many positive women in Asia experience extreme levels of discrimination and violations of their rights in relation to their reproductive health. Many face degrading treatment within maternal health services and receive little or no information related to their sexual or reproductive health care. Many women

**...strategies to prevent unwanted pregnancies among positive women have largely been forgotten...**

are coerced into abortion or sterilisation, because of their HIV positive status. Constant messages of ‘*don’t get pregnant*’ result in some women avoiding healthcare during pregnancy, because of fear of discrimination, and thus missing out on appropriate antenatal care and ARV prophylaxis.

Many outdated practices continue in Asia, such as the use of Stavudine and delivery by caesarean section. The correlation between sterilisations and caesareans is of particular concern. Mechanisms are needed to regularly disseminate information on changing WHO Guidelines, so health departments can adopt more dynamic policies and procedures.

**Lack of information and support**

Many women want advice about how to get pregnant safely and deliver a healthy baby, but healthcare workers are generally unsupportive of positive women’s desire to have children. Women who disclose their HIV status to their doctor need information and support to establish a family, without judgment. They need to know the risks of formula feeding versus breastfeeding, caesarean sections versus vaginal delivery, and the benefits of ARV prophylaxis.

**...positive women are discouraged from pregnancy, and many do not want to become pregnant, but they are given no realistic means to avoid unwanted pregnancies...**

With adequate information, support and care, women can have successful pregnancies.

Appropriate and ongoing training of positive women

as counsellors and educators is critical to increase understanding of HIV-positive women’s sexual and reproductive health and rights (SRHR).

However, few positive women’s networks are

funded to provide peer support or education. Financial support is needed for positive women’s organisations at national and regional level to enable positive women to advocate for their rights to sexual and reproductive healthcare.

Cost was repeatedly mentioned as a barrier to accessing services. This is consistent with findings from APN+’s earlier study on access to HIV services in Asia,<sup>3</sup> which found that 79% of over 1300 women from six countries did not have adequate financial resources to access services, including transport. Often women spend all financial resources on the healthcare of their husband, and are subsequently widowed and poor. Women living with HIV need sustainable livelihoods, but have limited opportunities to pursue them, and economic support is missing from most HIV interventions.

**...healthcare workers are generally unsupportive of positive women’s desire to have children...**

**RECOMMENDATIONS**

**Invest in positive women’s organisations**

- Increase capacity of positive women’s organisations to respond to their needs
- Train positive women at national, provincial and local level about their sexual and reproductive health and rights and increase women’s capacity in decision making

- Facilitate positive women's capacity to advocate for their sexual and reproductive health and rights

#### Expand counselling

- Train and employ women living with HIV as counsellors at government testing centres
- Expand HIV counselling to include psycho-social/emotional support, ARV treatment, SRHR advice; consider couple and family counselling when women do not have decision-making authority; strengthen referral systems to healthcare services

#### Uphold positive women's rights

- Ensure governments fulfil their obligations to protect positive women's rights according to international treaties
- Ensure no woman is coerced into HIV testing, abortion, sterilisation or caesarean
- Ensure positive women have access to a range of contraceptive options that they can control, to avoid unwanted pregnancies
- Ensure WHO Guidelines on ARVs are adopted
- Ensure no positive woman experiences discrimination within the health sector
- Train obstetric and gynaecological service providers to be sensitive to the needs and rights of positive pregnant women; include training on quality of care and sexual and reproductive health and rights in clinical management and curriculum training of healthcare workers

- Integrate services to improve access, utilisation and follow-up, and reduce discrimination

#### Expand social security

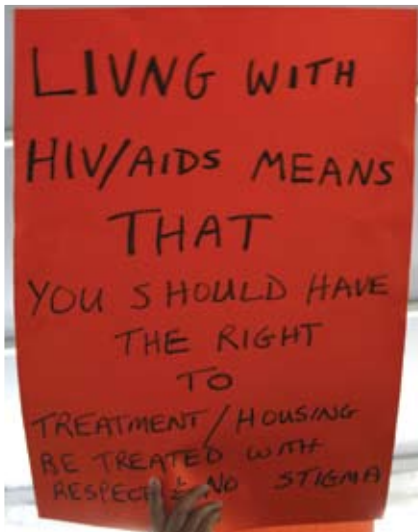
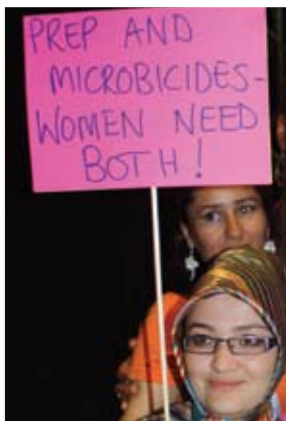
- Review national guidelines for social services requirements and expand social welfare
- Provide transport subsidy for mothers on low income to attend ARV centres
- Improve positive women's income generation capacity

#### FOOTNOTES:

1. The full report of this study is available at [www.apnplus.org/publications](http://www.apnplus.org/publications).
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# Messages from around the world



# Critical ingredients for effective HIV responses...

## Women and girls in a concentrated epidemic

**Rodelyn Marte, Rose Koenders, Katy Pullen**

*At the UN General Assembly High-Level Meeting on AIDS in June 2011, governments committed to a number of time-bound targets, including halving sexual transmission of HIV by 2015; eliminating gender inequalities and gender-based abuse and violence; and increasing the capacity of women and girls to protect themselves from HIV by 2015. Member States of the Association of Southeast Asian Nations (ASEAN) also reaffirmed their commitment to these goals in the ASEAN Declaration of Commitment: Getting to Zero New HIV Infections, Zero Discrimination, Zero AIDS-Related Death in November 2011.*

**M**any countries in Asia and the Pacific region, including ASEAN Member States, are experiencing concentrated epidemics with key affected populations identified as most-at-risk. While the 2011 Political Declaration notes that

*...each country should define the specific populations that are key to its epidemic and response based on the epidemiological and national context.<sup>1</sup>*

The Declaration also drew attention to the need to

*...focus on populations that, epidemiological evidence shows are at higher risk, specifically men who have sex with men, people who inject drugs and sex workers.<sup>2</sup>*

### FOCUSING ATTENTION ON KEY AFFECTED WOMEN AND GIRLS IN CONCENTRATED EPIDEMICS

Putting the issues of women and girls comprehensively on the HIV response agenda has been no easy task in Asia and the Pacific, which has a concentrated epidemic. Governments in the region committing to comprehensively focus on populations identified as most at risk is, in and of itself, a step forward. However, the specific needs of women and girls remain neglected and punitive laws, policies and practices, as well as stigma, discrimination and violence, continue to increase their vulnerabilities to HIV and block their access to sexual and reproductive health services.

A lack of sustained investment in women's leadership in the region, especially the leadership of key affected women and girls, coupled with the limited understanding among HIV stakeholders of the need for gendered approaches to HIV responses in concentrated epidemics, present ongoing challenges. Even where women and girls are empowered to speak out, where opportunities are provided for them to

advocate for their rights, resistance to taking-up issues of key affected women and girls is encountered from various quarters. Few openly advocate for women's empowerment and gender equality as critical ingredients for effective HIV responses. When it comes to matching the political rhetoric of gender with financial resources, the silence is deafening. The UNAIDS *Addressing Women, Girls, Gender Equality and HIV Action Framework* (2009), which held so much promise to achieve a 'comprehensive, gender-transformative AIDS response', stays on the shelf, gathering dust in the Asia and the Pacific Region.

With little or no funding, some progress has been made by initiating discussions, building strategic partnerships and mobilising support for the issue. In our individual capacities and as members of regionally-based organisations, mindful of not compromising the gains in focusing the HIV response to key affected populations, we have worked collectively to ensure that even in a concentrated epidemic setting, accountability is sought for what we, as an HIV community, are doing for key affected women and girls.

By sharing some of our experiences, including the challenges we continue to face, we invite discussions from our region and other parts of the world where concentrated epidemics exist, and where the needs and rights of women and girls most at risk of, and most affected by, HIV continue to be side-lined.

## DEFINING KEY AFFECTED WOMEN AND GIRLS IN CONCENTRATED EPIDEMICS

Efforts to address issues of women and girls in concentrated epidemics have been hindered in the region by a lack of common understanding of what populations constitute 'key affected women and girls' – which women and girls are most at risk of, and most affected by, HIV.

We have started to address this challenge by clarifying and defining key affected women and girls among Asia and Pacific HIV and AIDS organisations and communities. In an online consultation in August 2011, which aimed to stimulate discussion and dialogue on strategies for addressing the needs and rights of key

affected women and girls in HIV programmes, respondents shared that they understood key affected women and girls as: women and girls living with HIV; female sex workers; female drug users; transgender women; and the wives and the female partners of men who use drugs, men who have sex with men, and male clients of female sex workers.

The UNAIDS *Guidance for Partnerships with Civil Society, including people living with HIV and Key Populations* (2011) provides an implied definition of key affected women and girls. It notes that within key affected populations,

*...it will be especially important to recognize the needs of women and girls who work as sex workers, use drugs and/or are transgendered. In a number of settings, women and*

**...resistance to taking-up issues of key affected women and girls is encountered from various quarters...**

girls, as well as adolescents and young people, experience substantial and in some cases disproportional, impacts of the epidemic and may be considered key populations.<sup>3</sup>

A clear, common and explicit understanding of who are key affected women and girls is essential in advancing advocacy for their issues. For one, a common understanding opens up possibilities for solidarity, collaboration and dialogue among key affected women and girls across different groups. Furthermore, it counters the invisibilisation of women and girls within key affected populations.

#### *Evidence-based research*

More evidence-based research is needed to guide targeted interventions for most at risk and affected women and girls to ensure their specific needs are accurately addressed. Disaggregation of HIV and related data by age, sex and mode of transmission will strengthen this evidence.

#### *Partnerships and alliance-building*

The *UNAIDS Women, Girls, Gender Equality and HIV Action Agenda* recognises the importance of alliance-building at all levels of government and civil society, and of ensuring meaningful and equal participation of women and girls in the Agenda's implementation. Funds to bring together and create spaces for the meaningful engagement of and

engagement among key affected women and girls, in all their diversity, are difficult to mobilise, particularly in concentrated epidemics settings.

In response, the *Unzip the Lips* campaign<sup>4</sup> was formed in 2011, with the initial aim of enabling the voices of key affected groups of women and girls to be heard in the region's HIV response. Starting with mobilisations in the lead-up to the 10<sup>th</sup> International Congress on AIDS in Asia and the Pacific (ICAAP10), held in August 2011 in Korea, *Unzip the Lips* today comprises of an informal group of committed activists, individuals and organisations from the region working to address the needs and rights, and ensure the meaningful participation of key affected women and girls in the contexts of HIV and gender issues. *Unzip the Lips* has representation from and/or engagement with networks of people who use drugs, female sex workers, people living with HIV, young key affected populations; women's rights and sexual and reproductive health and rights organisations; as well as UN agencies.

#### *Policy advocacy*

Safeguarding and promoting the rights of key affected women and girls is critical if they are to protect themselves from HIV transmission, overcome stigma, discrimination and violence, as well as gain greater access to treatment, care and support. Efforts to reduce stigma, discrimination and violence need to be scaled-up to reduce the barriers to their uptake of HIV services, and to ensure that women

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

and girls are able to protect themselves from HIV, including in the context of intimate partnerships. These were the messages to policymakers from a session on key affected women and girls at the 10<sup>th</sup> International Congress on AIDS in Asia and the Pacific in August 2011.

Organised by women's rights groups and AIDS NGOs from the region, including the International Community of Women Living with HIV/AIDS (ICW), and with financial support from UN Women, the session facilitated a constructive dialogue between and amongst key affected women on barriers to their universal access to HIV services. Barriers discussed include lack of women-friendly services, especially for female drug users and transgender women; lack of participation in planning and implementation of health services, which was highlighted by positive women, female drug users, female sex workers and young key affected women; and the urgent need to improve sexual and reproductive health and HIV linkages at the community level. The double stigma often faced by key affected women within society, and the lack of programmes in place to address their unique needs, was also underscored. A key outcome from the session was the commitment from participants to engage with the *Unzip the Lips* campaign and to undertake greater alliance-building among and between networks and groups of key affected women in the region.

...when it comes to matching the political rhetoric of gender with financial resources, the silence is deafening...

In February 2012, a side event on Women and Girls was held at the Asia and the Pacific High Level Intergovernmental Meeting on HIV/AIDS and MDGs. Four women and a transgender from community organisations in the region shared their experiences and gave recommendations to governmental leaders, including the Chair of the Meeting, the President of Fiji, His Excellency Ratu Epeli Nailatikau. Amongst the speakers who highlighted the need to address the violations of rights of women living with HIV, one shared a story showing the linkages between gender-based violence and HIV. The speaker called upon governments for comprehensive programmes that address the power dynamics between women and men, sexual negotiations, and the need for reproductive and sexual rights of women and girls, so they are in a position to make their own decisions over their bodies. Other speakers highlighted the need to address the violations of rights of women living with HIV. The session ensured that during the negotiations of the meeting, women and girls should not be forgotten, and helped to build stronger political support for women and girls that went beyond the issue of mother-to-child HIV transmissions.

Across Asia and the Pacific, several national frameworks, policies and work plans recognise the importance of intimate partner transmission of HIV, and of developing and implementing strategies to effectively address this issue in

achieving the goal of reducing sexual transmission of HIV by 50 per cent by 2015. If HIV advocacy by and for key affected women and girls is not supported, and if key affected populations are not *'on board'*, addressing intimate partner transmissions cannot be achieved.

To this end, protecting and promoting the rights of key affected women and girls, as set out in the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW), is integral to reducing intimate partner transmission

of HIV and achieving the commitments and targets

**...have worked collectively to ensure that even in a concentrated epidemic setting, accountability is sought...**

set out in the UN 2011 Political Declaration on HIV/AIDS and the ASEAN Declaration of Commitment: Getting to Zero New HIV Infections, Zero Discrimination, Zero AIDS-Related Deaths.

#### *Turning the tide*

To achieve the commitments and targets mentioned above, the specific needs of key affected women and girls in the Asia and the Pacific regions must be recognised. The gains made are precarious, especially in the current environment, and we are a long way from turning the tide for HIV, and women and girls in Asia and the Pacific. Providing spaces for participation of women and girls will always remain important, and we hope

that our efforts have helped to broaden up these spaces for the future, and to ensure spaces will be secured for key affected women and girls to be meaningfully involved in decisions that affect their lives as women and girls, not only leading up to, but also beyond 2015.

#### **FOOTNOTES:**

1. 2011 Political Declaration on HIV/AIDS, para29.
2. *Ibid.*
3. [[www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2236\\_guidance\\_partnership\\_civilsociety\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2236_guidance_partnership_civilsociety_en.pdf)]
4. [www.unzipthelips.org](http://www.unzipthelips.org).

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# Who decides...?

## Achieving women's health and rights in times of economic austerity

*Despite political commitments, women and girls continue to face serious rights violations in the context of access to healthcare, particularly access to sexual and reproductive healthcare. This is further exacerbated for women and girls living with and affected by HIV.*

**Luisa Orza**

**T**he promotion and protection of the health and rights of women and girls are facing a greater threat than ever before in the wake of the global funding crisis.

Interrogating the implications of Round 11 cancellation of the Global Fund to fight AIDS, Tuberculosis and Malaria, and the budget cuts to the President's Emergency Plan for AIDS Relief (PEPFAR), women's rights activists at the Commission on the Status of Women agreed that it is time to urgently realise political commitments around women's and girls' right to health.

In the last decade, the vocabulary of women's rights has entered the popular imaginary. Yet, there has been and continues to be chronic underfunding of women's rights issues and programming, resulting in a failure to translate women's rights from the realm of the 'imaginary' to the realm of the 'real'. The lived complexity of women's rights and the challenges of exercising rights continue to go misunderstood or unacknowledged.

*People say they are 'always' hearing about women, funding for women, they're tired of it. How do we make*

*people understand why it's important and that it's more complex than that?'*<sup>1</sup>

In 2011, the Global Coalition on Women and AIDS (GCWA) worked with partners to support three women-led initiatives to explore these complexities. These comprised of:

- 1) a review of women's on-the-ground realities in relation to the commitments made in the 2001 UNGASS Declaration, and the 2006 Political Declaration, during the lead up to the 2011 High Level Meeting on HIV and AIDS;<sup>2</sup>
- 2) a review of the Global Fund Gender Equality Strategy to assess the progress, challenges and limitations of implementation of the strategy, and to make recommendations on the basis of lessons learnt;<sup>3</sup> and,
- 3) a consultation to ensure that the Global Plan towards the Elimination of New HIV Infection among Children by 2015 and Keeping Their Mothers Alive adequately responds to gender barriers impacting on women's access to prevention of vertical transmission programmes and services at a national level.<sup>4</sup>

The consultations created a space for women to talk in their own voices to describe their lived realities. They each revealed (and echoed) the myriad complex and nuanced ways in

**...the promotion and protection of the health and rights of women and girls are facing a greater threat than ever before in the wake of the global funding crisis...**

which women and girls are excluded from – and/or limited in their ability to access – information, healthcare services, psycho-social care, and other forms of social support; are vulnerable to structural inequalities, expressed through stigma, discrimination and violence; are excluded from meaningful participation in decision-making processes; and, are catered for primarily in their role as mothers and agents of reproduction, rather than as girls and women first and foremost. All of these realities are exacerbated when coupled with other factors of marginalisation, such as poverty, a positive sero-status, disability, or minority sexuality.

*We are very visible when we are pregnant and we need some services. But before and after pregnancy, where are we? We are invited to talk about programmes for PMTCT and nothing else.*

In the context of HIV, where women now make up

over 50% of people living with HIV globally, and 60% in sub-Saharan Africa; where young women account for up to 75% of people living with HIV in the 15 to 24-year-old age group; and women constitute the fastest growing population of new infections in several parts of the world<sup>5</sup>, the failure of policy and programming (and the corollary budgets and accountability mechanisms) to address the complexities described by these consultations is becoming increasingly visible.

Further, as the squeeze on global funding tightens, women's organisations, ministries and departments are under more and more pressure to prove that investments in programmes to address structural inequalities are not only effective, but that they constitute 'value for money'. The investment paradigm is a double-edged sword for women and girls. On the one hand, the positioning of gender equality as a critical enabler in the HIV response (without which return on investment cannot be assured) has advanced the integration of gender equality and sexual and reproductive health and rights into mainstream discourse.

On the other, as the global economic crisis worsens, and the emphasis on 'value for money' grows, systems cannot fail to pit the worth of

**...the lived complexity of women's rights and the challenges of exercising rights continue to go misunderstood or unacknowledged...**

one life against another. Ancient oppressions re-emerge. The old order reasserts itself. No longer the 'luxury' of resourcing women's health and rights, if to do so does not also boost the economy.

*We need to question the notion of investment as being around growth and economics and not necessarily about resourcing women to access their rights.*

*We need to remember that if we get confined to a framework that is based on a scarcity model we will be confined in what we are doing.*

It is clear that women activists and advocates need to re-position ourselves to push back against the walls that are closing in on women's rights. We need to push back on the investment language and on the maternal health language. Women's health is not about economic development, it is about rights – all our rights, throughout all our life – not only when

**...these realities are exacerbated when coupled with other factors of marginalisation, such as poverty, a positive sero-status, disability, or minority sexuality...**

those rights serve to protect the products of our womb.

We need to reclaim the agenda from the position of strength, to reclaim our own voice as a voice of experience – and we need to

do so visibly. The community conversation – women's lived realities, as echoed and re-echoed so often in the consultations mentioned above – need to be as much a part of this, as the political mobilisation of women.

*Why are we in this situation where we're begging for resources; we're presenting this evidence that we have a problem? We are half the human race! Isn't that enough?*

We need to expand the agenda and bring the content of human rights into the agenda, reclaiming the multiple dimensions of rights, so that when we are talking about the right to health, we are not just talking about access to services; when we are talking about sexual and reproductive rights, we are not just talking about maternal and child health; when we are talking about the right to life, we are not pitting our own life against that of our child, partner, sister or friend. By expanding the conversation on rights, and populating it with our experiences and realities, we can claim multiple spaces as legitimate spaces for these conversations – the World Health Assembly; the International Labour Organization; and Rio+ 20 on sustainable development.

And we need to demand accountability to look at where resources are going. Why has Round 11 failed? What are national governments doing with their money? Who is holding them to account?

*We should never be the victim. We are there – we can stand our own ground – we don't need to ask to be listened to.*

**Women's rights activists, participants in the meeting, drafted the following statement calling upon governments, UN agencies, and civil society at all levels to:**

- *Realise in full women's and girls' entitlement to comprehensive healthcare, including sexual and reproductive healthcare during all stages of their lives and regardless of HIV status, sexuality, and gender identity*
- *Provide space in all decision-making fora for women living with and affected by HIV, and women living in contexts of marginalisation, to give voice to their experiences and realities and to highlight the complexities and challenges of meeting their health entitlements; and, ensure their meaningful involvement in identifying and implementing solutions to address these*
- *Recognise the public health imperative of ensuring women's and girls' human rights are realised in all aspects of their lives*
- *Expand and secure an even distribution of available resources across the whole spectrum of healthcare to ensure that adequate funding is available both within and beyond maternal healthcare so that women and girls can claim their right to health; in so doing, guarantee adequate funding at the country level for all four prongs of the Global Plan to End Vertical Transmission and Keep Mothers Alive*
- *Ensure adequate budget allocations and accountability mechanisms for the translation of political commitments to protect and advance women's and girls' rights in the context of HIV into programmes and interventions which have the potential to transform the lived realities of women and girls*
- *Prioritise inter- and multi-sectoral dialogue and engagement between all relevant stakeholders, especially women living with HIV, to assure that women's and girls' rights are promoted, protected and comprehensively resourced during times of financial crisis*

**FOOTNOTES:**

1. All quotes are from participants in the CSW 2012 side event '*Achieving Women's Health in Times of Economic Austerity: Interrogating the implications of Round 11 cancellation of the Global Fund to Fight AIDS, Tuberculosis and Malaria, and the budget cuts to PEPFAR*', hosted by AIDS Legal Network, ATHENA, Fundación para Estudio y Investigación de la Mujer (FEIM), the International AIDS Women's Caucus (IAWC), and the World YWCA.
2. Consultation led by ATHENA Network. [www.womenandaids.net/CMSPages/GetFile.aspx?guid=4b2bf719-a503-416f-bfd9-d44d8e5308ee]
3. Consultation led by FEIM. [www.womenandaids.net/CMSPages/GetFile.aspx?guid=82f90464-a0c8-4361-be83-beb33c6d422d]
4. Consultation led by AIDS Legal Network (ALN). [www.womenandaids.net/CMSPages/GetFile.aspx?guid=4efe8aa8-b916-442d-918f-21271b8542e3]
5. UNAIDS. 2010. *Global Report: UNAIDS Report on the Global AIDS Epidemic*.

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# Intersecting factors must be addressed...

## Sexual and reproductive health and rights, HIV and the African Women's Protocol

**Karen Stefiszyn**

*It is well-evidenced that gender inequality greatly impacts on the extent to which women are in the position to make informed sexual and reproductive choices; to access healthcare services; and to ultimately benefit from available HIV information, prevention, treatment, care and support programmes and interventions. Moreover, the same socio-cultural and religious values and gender norms, which increase women's risks and vulnerabilities to HIV, also frequently act as barriers to their ability to access and benefit from services. Thus, a vicious cycle is created whereby women's inability to achieve sexual and reproductive health and rights increases their susceptibility to HIV acquisition, which in turn exacerbates barriers to achieving sexual and reproductive health and rights.*

**T**he overarching goal of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol) is to bring about gender equality in Africa, the converse of which is fuelling the spread of HIV on the continent. Women's human rights in Africa are enumerated in the Protocol with

corresponding and comprehensive measures to be taken by states in order to promote, protect, and fulfil these rights. It addresses many of the root causes of the disproportionate spread of HIV amongst young women in Africa, such as sexual violence and early marriage, as well as factors that exacerbate the effects of HIV infection on the enjoyment of human rights, such as the denial of inheritance rights.

Health and reproductive rights are provided for in Article 14 of the African Women's Protocol, including women's rights to *inter alia*: control their fertility; choose any method of contraception; decide whether to have children, the number of children and their spacing; and to receive family planning education. The African Women's Protocol is the first binding international human rights treaty to guarantee the right to abortion under qualified circumstances, as well as the right to be protected from HIV infection, thus offering greater protection for the reproductive rights of women, than any other legally binding international human rights instrument. The provisions explicitly relating to HIV are grounded in the African Women's Protocol reiterate at least two important points: that HIV is a human rights issue; and that HIV has a disproportionate impact on African women and girls. Also the inclusion of rights relating to HIV explicitly under health and reproductive rights confirms that challenges to women's reproductive health are compounded in the context of the HIV pandemic.

Along with the provisions in international human rights law specific to reproductive health rights, numerous other human rights principles, enshrined in the African Women's Protocol and other defining international human rights instruments, are applicable to the promotion and protection of positive women's sexual and reproductive health rights. These provisions include, but are not limited to: the right to equality and to be free from all forms of discrimination; rights relating to individual freedom, self-determination and autonomy; rights regarding survival, liberty, dignity and security; rights regarding family and private life; rights to information and education; and the right to the highest attainable standard of health. Violations of women's reproductive health and rights are cross-cutting and inhibit the enjoyment of numerous other rights. Women living with HIV have the same rights concerning their reproductive health as other women, but they also have needs and concerns that are unique and may be confronted with violations of their rights on the basis of their HIV status. These are elaborated below.

**...offering greater protection  
for the reproductive rights  
of women...**

*Pregnancy and discrimination*

The right to health is to be exercised without distinction of any kind, such as race, ethnic group, colour, sex, language,

religion, political or other opinion, national and social origin, wealth, birth or other status.<sup>1</sup> States that discriminate against women living with HIV by failing to protect, promote, and fulfil their right to the highest attainable status of health, are doing so not only on the basis of sex, but also on the basis of 'other status', which the UN Commission on Human Rights has determined to apply to health status, including HIV.<sup>2</sup>

A considerable number of healthcare practitioners lack sufficient knowledge on HIV and human rights, and on the rights of women living with HIV in particular, resulting in discrimination and stigmatisation in healthcare settings, including obstetrical and gynaecological care.<sup>3</sup> However, States have a responsibility to ensure that health facilities, goods and services, including the underlying determinants of health, are accessible to all, especially the most vulnerable or marginalised sections of the population, without discrimination.<sup>4</sup>

Individuals, including health professionals, tend to stigmatise women living with HIV, in particular those seeking services related to reproductive decision making. A study in Zimbabwe, for example, revealed negative experiences by women living with HIV while seeking reproductive health services.<sup>5</sup> Some of the participants in the study admitted to non-disclosure of their HIV status to health workers in order to avoid discrimination.<sup>6</sup> One participant had not received proper care when delivering her child, because the healthcare workers feared HIV transmission.<sup>7</sup> Others reported being scolded by health workers for getting pregnant.<sup>8</sup> According to another report, a woman in Namibia was ignored by healthcare workers when seeking information on HIV and pregnancy

**...violations of women's reproductive health and rights are cross-cutting and inhibit the enjoyment of numerous other rights...**

and was told 'you are HIV-positive and you are pregnant, your baby already die [sic]'.<sup>9</sup> In an environment where HIV-related stigma manifests, women living with HIV can be deterred from seeking services and consequently endanger their own health and, if pregnant, the health of their unborn children.

Discrimination against pregnant women, particularly pregnant women living with HIV, persists despite international human rights obligations to prohibit discrimination against women in every area. Violations of women's sexual and reproductive health and rights, which are discriminatory and are based on their HIV status, have the effect of impairing and nullifying the recognition, enjoyment and exercise of their rights as envisaged by CEDAW and the African Women's Protocol. Further, the same violations impede women's access to and benefit from HIV prevention, care, treatment and support information and services, reducing their ability to protect themselves, their partners and their actual or future infants from HIV acquisition.

**The right to control fertility**

The right to control one's fertility means the right of a woman to reproductive autonomy, including her right to decide

freely and responsibly if, when, and how often to reproduce.<sup>10</sup> Violations of reproductive autonomy negatively affect women's empowerment, of which being in a position to make free and informed decisions is an integral component. There are numerous impediments in Africa to the realisation of this right. Social norms and cultural values place significant pressure on women to bear children, and women's value to family and society is often determined by their fertility. Many women desire children for a variety of other personal reasons and cannot imagine a life where such a desire is left unfulfilled. Other women do not want to have children at all, or may not want to have more children, yet may be unable to avoid pregnancy, due to an inability to negotiate safer sex, or due to a lack of access to adequate information provided by well-resourced and informed family planning services. When confronted with an unplanned and unwanted pregnancy, many women are unable to safely terminate the pregnancy, due to prohibitive abortion laws in their country.

The right to control one's fertility exists regardless of HIV status. More than 80% of all women living with HIV and

**...violations of women's sexual and reproductive health and rights ... have the effect of impairing and nullifying the recognition, enjoyment and exercise of their rights...**

their partners are of reproductive age.<sup>11</sup> An enabling environment for informed choices is required in order for women living with HIV to choose whether to have children, how many, and when. However, HIV gives rise to a number of complicated issues in different areas. Despite increased availability of state-provided treatment, the health and well-being of women living with HIV can be threatened during pregnancy and labour. There is also a risk of passing HIV to the infant via perinatal transmission. In addition, women living with HIV face strong pressures from community members and healthcare providers not to become pregnant and have children, either because of the risk of perinatal HIV transmission or out of concern for the welfare of children raised by parents who may die prematurely of AIDS-related illnesses. A considerable number of service providers are also of the opinion that pregnancy ought to be prevented at all costs in women living with HIV.<sup>12</sup>

On the other hand, many women living with HIV still maintain their desire to have children, irrespective of their HIV status.<sup>13</sup> A study in South Africa found that personal desires and family and societal expectations frequently outweighed the influence of HIV status in determining whether or not to have children.<sup>14</sup> The same study cited hope, happiness and a reason for living as factors influencing the desire for children amongst women and men living with HIV.<sup>15</sup> However, concerns were noted by the study participants about childbearing, including the health of the infant, the risk of deteriorating health during pregnancy, fears of transmitting HIV to an uninfected partner while trying to conceive, and the possibility of dying and condemning a child to orphanhood.<sup>16</sup> Along with the

importance assigned to childbearing in Sub-Saharan Africa and the accompanying social pressure for women to bear children, as well as personal desires for motherhood, women living with HIV are confronted with unique challenges that influence their reproductive decisions.

These scenarios create a conflict for women living with HIV and impact on their right to make free and informed choices, irrespective of whether it relates to a desire to reproduce or to the choice to inhibit reproduction. Either way, the notion of choice is an imperative factor in the right of women to make decisions concerning fertility free of coercion.

Control over one's body and fertility is more easily exercised in situations where one is informed and empowered to make relevant decisions, particularly when those decisions comprise the additional considerations brought about by living with HIV. In Africa, however, many women live in a context of poverty and disempowerment – often entailing lack of access

to information – which exacerbates inherently unequal power relations between themselves and those encountered within the healthcare system.

This may leave women susceptible to directive counselling or outright coercion, especially where decision-making is already compromised

**...violations of reproductive autonomy negatively affect women's empowerment, of which being in a position to make free and informed decisions is an integral component...**

by familial, societal and/or internalised HIV-related stigma and/or a lack of accurate information regarding safe pregnancy and childbirth for women living with HIV. Healthcare workers, untrained in human rights – and often also overstretched, under-resourced, and lacking accurate, up-to-date information on HIV care and treatment – may act on their own judgement of ‘*what is best*’ both for the woman and for the unborn child, and in doing so, potentially violate women’s rights. A human rights-based approach to sexual and reproductive health and HIV, which would require legislation, policies, and guidelines based on internationally accepted human rights norms to be enacted and implemented, is necessary to protect the rights of women living with HIV to control their fertility.

#### *Family planning and access to contraceptive services*

The 2011 Millennium Development Goals Report indicates that in Sub-Saharan Africa, one in four married women has an unmet need for family planning based on the latest available data from 2008.<sup>17</sup> The right to choose whether and when to have a child lies at the core of reproductive rights. The right

**...a human rights-based approach ... is necessary to protect the rights of women living with HIV to control their fertility...**

to family planning is enshrined explicitly at the African regional level in the Women’s Protocol.<sup>18</sup> In order for women living with HIV to be in a position to make informed decisions regarding

childbearing, women must be informed about and given access to safe, effective, affordable, and acceptable methods of family planning of their choice along with other reproductive healthcare services, and the means to utilise such facilities.<sup>19</sup>

There is a direct relationship between a woman’s fertility rights and the contraceptive services available. While the World Health Organisation (WHO) has confirmed the effectiveness and safety of the use of contraceptives by women living with HIV, limited and/or denied access to safe and effective contraceptive services severely compromises the rights of women living with HIV. A study conducted in Botswana, for example, indicates that women’s desire to control their fertility is hampered by the limitation of contraceptive options they face.<sup>20</sup> In Zambia, women living with HIV reported difficulty in asking for, and accessing forms of contraceptives other than condoms, and one woman reported being told that

*...requesting contraceptives is a confirmation that you are not using condoms, exposing others to risk and exposing yourself to re-infection and more infections.*<sup>21</sup>

Even where contraceptives are available, women often do not possess adequate information to make an appropriate choice.<sup>22</sup> There is a need for explicit policies that recognise the right to reproductive choice for individuals living with HIV, including improved access to contraception and other reproductive healthcare services.

The difficulties women face in negotiating the circumstances of sex, including condom use, are widely recognised and understood. To address these challenges, increasing access to

...women must be informed about and given access to safe, effective, affordable, and acceptable methods of family planning of their choice...

and quality of family planning services must be linked with ongoing initiatives towards gender equality, particularly through transforming gender norms, education, economic empowerment, and addressing all forms of violence against

of their sexual and reproductive health. Moreover, such laws consistently generate poor physical health outcomes, resulting in deaths that could have been prevented, morbidity and ill-health, as well as negative mental health outcomes, not least because affected women risk being thrust into the criminal justice system. Creation or maintenance of criminal laws with respect to abortion may amount to violations of the obligations of States to respect, protect and fulfil the right to health.<sup>26</sup>

women. Where gender inequalities prevail, women are least in a position to decide freely on whether or not to bear children regardless of the availability and quality of services in place.

#### *Access to legal abortion*

Restrictions on abortion have devastating effects on women's health and rights. In Africa, the risk of dying following unsafe abortion is the highest worldwide, where 14% of maternal deaths are due to unsafe abortions.<sup>23</sup> A women's rights NGO in Malawi reported that unsafe abortions contribute to about 30% of Malawi's maternal mortality rates.<sup>24</sup> Many countries in Africa have restrictive abortion laws which violate women's rights to reproductive autonomy and fail to take into account the reality of women's lives. Prohibitive abortion laws not only affect women's health and well-being; but the denial of abortion services also violates the right to equality and non-discrimination.<sup>25</sup>

*These laws infringe women's dignity and autonomy by severely restricting decision-making by women in respect*

WHO defines 'unplanned pregnancy' as a pregnancy that is not expected, and 'unwanted pregnancy' as a pregnancy that for a variety of often overlapping reasons is both unexpected and undesired.<sup>27</sup> This definition indicates that a pregnant woman decides of her own free will whether or not that pregnancy is undesired. Considering that 38% of pregnancies are unplanned, impediments to reproductive choice must be considered.<sup>28</sup> Many pregnancies, for example, are the result of sexual violence and rape, including within marriage, which in Malawi and Botswana – among many other countries in Africa – can occur with impunity in the absence of legislation addressing marital rape. In many countries in Sub-Saharan Africa, children who are forced into early marriage give birth to children. Other unintended pregnancies result from ignorance as a result of limited and/or denied access to sex education including information on family planning and contraceptives. Many women cannot negotiate safer sex in their relationships and/or do not have consistent access to contraceptive methods for a variety of reasons, including in situations where reproductive

health services are only available in centres beyond the reach of rural women. Women living with HIV can have serious negative health consequences from unplanned pregnancies if, for example, they do not have access to relevant treatment, information and support services, or are not in an optimum state of health pre-conception. In addition, research indicates that women living with HIV are among women who choose to terminate pregnancies including in countries with numerous legal restrictions on abortion.<sup>29</sup> In these circumstances, terminations run a high risk of being carried out by persons lacking the necessary skills and in circumstances that lack minimal medical standards. Complications from unsafe abortion have been cited as one of the major reproductive health problems facing the sub-region.<sup>30</sup>

UNAIDS recommends that women living with HIV should have a right to choose whether to terminate a pregnancy upon

**...where gender inequalities prevail, women are least in a position to decide freely on whether or not to bear children regardless of the availability and quality of services in place...**

learning of their HIV status; and that they should be supported to do so without judgment.<sup>31</sup> Some legal experts believe that it is unnecessary to specifically mention HIV as one of the grounds to terminate a pregnancy, because a positive HIV diagnosis

should entitle a woman to access a legal abortion where abortion is permitted to protect a woman's health or life.<sup>32</sup> This recommendation by UNAIDS should, however, not be used to coerce or pressure women living with HIV to have an abortion. The International Community of Women Living with HIV (ICW) has reported that their members have sometimes felt that healthcare workers present abortion as the only option for pregnant women living with HIV, and that they have felt coerced into having an abortion.<sup>33</sup>

**Forced or coerced sterilisation**

Research carried out by ICW and others documented 40 instances of coerced or forced sterilisation in Namibia, whereby informed consent for the procedure was not adequately obtained. The research found that

*...consent was obtained under duress, consent was invalid as the women were not informed of the contents of the documents they signed, medical personnel failed to provide full and accurate information regarding the sterilisation procedure.*<sup>34</sup>

Women were also asked to provide signed consent for sterilisation in order to access other services including abortion and caesarean and to receive assistance with childbirth.<sup>35</sup> Similar cases have been documented in South Africa and Zambia.<sup>36</sup> Three Namibian women are currently seeking redress in the High Court. If local mechanisms are exhausted without success, then these cases should be brought before the African Commission on Human and

Peoples' Rights, the African Court, or before the CEDAW Committee.

Forced or coerced sterilisation or abortion adversely affects women's physical and mental health, and infringes upon the right of women to control their fertility and to decide on the number and spacing of their children.<sup>37</sup> Forced or coerced sterilisation violates other human rights as well, including the right to be free from cruel, inhuman and degrading treatment; the right to liberty and security of person, the right to bodily integrity; and the right to equality and to be free from discrimination. The International Federation of Gynaecology and Obstetrics (FIGO), in outlining ethical considerations in sterilisation, stated that no incentives should be given, or coercion applied, to promote or discourage any particular decision regarding sterilisation.

Withholding other medical care by linking it to sterilisation is unacceptable.<sup>38</sup> As sterilisation is permanent, the decision made by the woman should be based on voluntary informed choice and should not be made under stress or any kind of duress.

Restrictions on women's reproductive choice are bound to further fuel stigma and discrimination against women living with HIV, subjecting them to double discrimination. Forced sterilisation, for example, will also lay

**...considering that 38% of pregnancies are unplanned, impediments to reproductive choice must be considered...**

**...restrictions on women's reproductive choice are bound to further fuel stigma and discrimination against women living with HIV, subjecting them to double discrimination...**

an additional favourable ground for further discrimination in societies which emphasise fertility and childbearing as a defining factor in women's successful contribution to the extended family and society as a whole.

#### **CONCLUSION**

Barriers to controlling one's fertility, unmet family planning needs and lack of access to contraceptive services, restrictive abortion laws, and coerced or forced sterilisation, are all issues confronted by women living with HIV, which threaten their rights guaranteed under the African Women's Rights Protocol. National legal frameworks must be strengthened to address the HIV-related discrimination, which fuels violations of these enshrined rights.

At the same time, other non-legal measures, such as awareness-raising and education campaigns, must be undertaken towards the same end.

In order to create an enabling environment for women to exercise their right to control their fertility, intersecting factors, such as inequality and violence against women, must be addressed through law and policy and accompanying implementation mechanisms with dedicated adequate financial resources. The 23 African states

...held accountable to commitments to promote, protect, and fulfil the rights of women living with HIV, including their health and sexual and reproductive rights...

women living with HIV, including their health and sexual and reproductive rights.

that have not yet ratified the African Women's Protocol should be encouraged to do so in order for them to also be held accountable to commitments to promote, protect, and fulfil the rights of

#### FOOTNOTES:

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2. Office of the United Nations High Commissioner for Human Rights, 2003.
3. Resolution adopted by the General Assembly 60/262 Political Declaration on HIV/AIDS, 2006.
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6. *Ibid*, p168.
7. *Ibid*.
8. *Ibid*.
9. ICW. 2009. *The forced and coerced sterilisation of HIV positive women in Namibia*. International Community of Women Living with HIV. [www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf]
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14. Cooper, D. et al. 2007. "'Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa'. In: *Social Science and Medicine*, 65, p274.
15. *Ibid*, p277.
16. *Ibid*, p279.
17. The Millennium Development Goals Report 2011. [www.un.org/millenniumgoals/11\_MDG%20Report\_EN.pdf]
18. Article 14(1)(b) of the African Women's Protocol.
19. Cairo Programme of Action (note 5 above) para2.
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21. Southern African Litigation Centre. 2009. 'Brief summary of sexual and reproductive health and rights concerns of women living with HIV in Zambia'.
22. *Ibid*.
23. UN Women. *2011-2012 Progress of the World's Women: In Pursuit of Justice*. New York, p42.
24. A list of critical issues to the 6th periodic report of Malawi on CEDAW. Identified by WLSA Malawi. Prepared and submitted by S White & T Kachika. January 26, 2009, p8.
25. CEDAW General Recommendation 24, para14.
26. Grover, A. 2011. Interim report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN General Assembly, A/66/254, para21.
27. WHO. 2006. *Unsafe Abortion: The Preventable Pandemic*. Geneva: WHO.
28. Alan Guttmacher Institute, This report indicates that of the estimated 210 million pregnancies that occur throughout the world each year, 38% are unplanned. In developing countries, of the 182 million pregnancies occurring each year, an estimated 36% are unplanned and 20% end in abortion.
29. See for example De Bruyn, M. 2005. *HIV/AIDS and Reproductive Health: Sensitive and Neglected Issues. A Review of the Literature. Recommendations for Action*. Chapel Hill, NC: Ipas. [www.ipas.org/Publications/asset\_upload\_file268\_2956.pdf]. The same findings were made by WHO 'Women and HIV and mother-to-child transmission' Fact sheet 10. [www.who.int/health-service-delivery/HIV\_aids/English/fact-sheet-10/index/html].
30. Sexual and Reproductive Health Strategy for the SADC Region 2006-2015, September 2006. The aim of the strategy is to provide a policy framework and guidelines to accelerate the attainment of healthy sexual and reproductive life for all SADC citizens.
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33. ICW, 2008.
34. ICW, 'Overview of ICW's work to end the forced and coerced' [sic]. [www.icw.org/node/381]
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# Taking a stand...



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