



**Sexual and Reproductive Health
of HIV Positive Women and Adolescent Girls:
A Dialogue on Rights, Policies and Services**

**Global Electronic Forum
Report on Results**

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Introduction

i) Background

In April and May of 2005, UNFPA and EngenderHealth, in collaboration with the International Community of Women Living with HIV/AIDS (ICW), Ipas and the Program on International Health and Human Rights at Harvard University's FXB Center for Health and Human Rights, hosted two parallel electronic discussion fora on the subject of sexual and reproductive health (SRH) policies, services and human rights for HIV-positive women. One forum, moderated by Harvard and Ipas, was open to all professionals and women with HIV/AIDS, with over 300 individuals invited to participate from a wide variety of international women's health, human rights, HIV advocacy and development organizations. (For ease of reference, this forum will be called the "interdisciplinary" forum.) The other forum, moderated by ICW, was open only to HIV-positive women, to ensure the existence of a "safe space" to confidentially discuss experiences; invitees were members of ICW's vast international network.

ii) Methodology

The first month of each forum focused on human rights and advocacy as they affect the ability of HIV-positive women to access appropriate sexual and reproductive health services; the second month centred on the availability and quality of SRH services, and on the programme policies which shape those services. The ultimate aim of these fora was to provide input for EngenderHealth and UNFPA's joint project to improve care for HIV-positive women -- to gather insights into current policies and provision of services for HIV-positive women, including successes and challenges, priorities for improvements, and current gaps and barriers to services. This information will feed into the development of a rights-based framework offering policy and programmatic guidance for providing sexual and reproductive health services for HIV-positive people living with HIV, especially women and young people, as well as a training package for sexual and reproductive health programme managers and providers. Both publications are slated for publication by UNFPA and EngenderHealth in 2006.

While over 120 individuals signed on as members of the interdisciplinary forum, most did not submit written contributions over the course of the two months.¹ The ICW forum had more participation, with 21 contributors (out of 90+ registrants) and 36 postings. We can only speculate as to the reasons for this².

¹ In the first month, there were 7 comments from participants; in the second month, there were 6 substantive comments and 2 additional messages announcing RFPs or petitions. (These numbers do not include the comments of moderators or EngenderHealth staff involved with e-forum development.) In the first month (rights component), week two yielded the most responses (6), while weeks three and four yielded none. Responses during the second month (services and program policies component) were more spread out, with 3 responses the first week, and 1-2 in each subsequent week.

² Some people mentioned "e-forum fatigue" as a possibility, as other electronic fora on reproductive health issues had transpired in previous months. Another possibility is that the initial human rights-related questions tended toward the abstract and perhaps were harder for participants to "jump into." Moderators sought to rectify this by supplying participants with case studies and encouraging discussion based on personal experience.

Nevertheless, what the e-forums may have lacked in quantity they made up for in the substantive content and depth of responses. This report is an attempt to capture the major themes, weaving together the responses of both fora. As with all qualitative data, caution should be used in making generalizations, particularly given the level of response. However, the key findings are supported by other qualitative research on this topic, including a recent EngenderHealth/UNFPA study conducted on SRH for HIV positive women in Brazil, Ethiopia, and the Ukraine.

iii) Summary of Main Issues Raised

The overarching issue - at the root of barriers to care, lack of services and low quality of existing care - was the high degree of stigma and discrimination experienced by HIV-positive women. This and resulting violations of their human rights were prominent themes throughout the duration of both fora, and provided a backdrop to virtually all other topics discussed.

Another major theme was the lack of the most basic services responsive to the needs of HIV-positive women. Participants in the ICW e-forum felt that on the whole, programmes are not specifically tailored to their reproductive and sexual health needs. Women face significant barriers at the domestic, community, regional and national level in realizing their rights and sexual and reproductive health. Among those mentioned included: inaccessibility of health centres; lack of respect for female patients' rights and judgmental attitudes among health care workers.

For participants in the interdisciplinary forum, the issue of health care provider attitudes appeared to strike a particular nerve, with a flurry of responses related to negative provider attitudes toward HIV-positive patients, and concerns about discrimination and stigma in the health care setting. Other responses were sympathetic to health care workers toiling in resource-challenged settings, with neither the training nor the equipment/supplies to care for patients safely. Suggestions were made regarding ways to improve counselling services for HIV-positive women seeking SRH care, as well as ways to improve in-service and pre-service training for providers.

II. Rights, Policies and Services

i) Rights

While the two major topics – “human rights and advocacy” and “SRH services and programmes and policies” - were focused on separately during consecutive months of the fora, themes of human rights violations in the context of SRH services permeated all discussions and overlapped considerably. As it seemed more useful to discuss them together, issues of human rights and how they affect service provision are considered jointly throughout this report. For reference to the original topic areas, the weekly schedule of questions is available in Appendix 1.

Stigma, discrimination and rights violations are addressed as an overview in the first section of this report. Subsequent sections concern provider attitudes and treatment; testing, counselling and disclosure; pregnancy-related decision-making; experiences of marginalized women; and the effectiveness of human rights documents and advocacy. The concluding section discusses gaps in services identified by participants, and offers suggestions on improving services and maintaining or widening the scope of human rights, going forward.

Human Rights Documents and Advocacy

The human rights segment of the e-forum posed questions on the effectiveness of existing human rights documents and their potential use for advocacy, including the following:

- How have international HR documents or advocacy efforts facilitated access to SRH these services for HIV-positive women, if at all?
- What accountability mechanisms exist for them? How can we advocate for stronger enforcement of human rights?
- What role can/should international documents ideally play in furthering HIV-positive women's access to sexual and reproductive health services? Have any international or national human rights documents “trickled down” to have impact on the ground?

[A moderator added these key points to illuminate the discussion:

- At the policy level, international and national policy-making bodies can work to ensure that international documents are sensitive to the needs of HIV positive women.
- At the programmatic level, rights can be integrated into the design, implementation, and monitoring and evaluation of programs so that concerns with issues such as discrimination, and participation at every stage are addressed.
- Advocacy is another important tool that can be used by individuals and organizations to promote human rights through reaching out to policy makers and other influential groups, linking with activists working on related issues (such as groups focused on family planning, violence against women, and poverty), and translating international human rights norms to the work and concerns of local communities.
- The "human rights approach" to HIV/AIDS can be an effective way to protect the rights of people infected with HIV, for example in putting together legislation and policies. What is not clear, however, is how these laws have impact on people at the community level, particularly HIV positive women. The protection of rights depends on the government's commitment to rights and the ability of the community to assert

its rights. A significant number of States continue to deny that HIV is a rights issue, or disallow scientifically proven HIV interventions on the grounds of religion, custom, or law. This is particularly true in relation to the vulnerability of poor women to HIV in developing countries, and our inability to challenge violations of women's equality, autonomy, and bodily integrity.]

These questions elicited several responses from the ICW forum, with very few responding from the interdisciplinary forum.

HR Documents' Utility for Women with HIV

One contributor had questions about whether any documents exist specifically to protect the rights of women with HIV:

'I also think it would be good to know exactly what treaties and agreements on sexual and reproductive rights exist which we can use as tools and whether they protect HIV-positive women specifically... are there HIV positive women specific treaties or agreements relating to our sexual and reproductive rights that we can use as tools? I can't think of any - in which case there is a gap that needs to be filled.'

Several people responded with ideas for resources:

'I am thinking of CEDAW - Convention for the Elimination of all Discrimination Against Women. I am enclosing a link from the Women's United Nations Report Network which lists a whole range of declarations - mostly on human rights. <http://www.wunrn.com/reference/reference.htm>.'³

'In my experience there are declarations that enshrine the rights of women such as CEDAW and declarations that enshrine the rights of PEOPLE living with HIV/AIDS such as UNGASS partially does. However, I have yet to come across a declaration signed by States that enshrines or even mentions the rights of HIV positive women. This means as activists we have to work harder to ensure that policymakers understand our rights.'⁴

³ Response from the moderator: *There are no specific treaties (conventions) that deal exclusively with people living with HIV/AIDS. Treaty Monitoring Committees are groups of experts that receive periodic reports from governments on their compliance with conventions and make recommendations about compliance to governments (called Concluding Observations). These Committees have commented on the situation of people living with HIV/AIDS in Concluding Observations to various governments. The CEDAW Committee is preparing General Recommendation 26 on discrimination – General Recommendations provide guidance to governments on how to interpret and apply treaties. Ipas and the Center for Reproductive Rights wrote to the CEDAW Committee about violations of HIV-positive women's reproductive rights and asked them to address these in the new General Recommendation.*

⁴ Response from the moderator: *When treaties are ratified by governments, they have the authority of law. CEDAW is such a treaty that governments oblige themselves to observe. Declarations – like the UNGASS Declaration, Beijing Platform for Action and ICPD Programme of Action – are statements of intent by government; they are supposed to live up to what is stated in the Declarations but these do not have the status of law like treaties. However, Treaty Monitoring Committees do refer to Declarations when they are making recommendations to governments.*

'Although not signed by States a powerful declaration in my view is the Buenos Aires Declaration 2004 - Human Rights, Women and AIDS. This has been signed by a number of churches and as we know church leaders can be powerful influences in our daily lives. [This declaration is on the ICW website].'

Stigma, Discrimination and Rights Violations

Stigmatizing and discriminatory attitudes toward HIV-positive women (and men) lie at the root of many human rights concerns and violations, and result in poor quality of care. Judgmental attitudes – whether from health care providers or the wider community - can be huge stumbling blocks for people living with HIV/AIDS. Indeed, issues of access to care, treatment and support cannot be considered in isolation, but must be viewed within this larger context, especially within prevailing cultures that treat women unequally and hinder their autonomy. Community-wide support structures are often scarce – even in more developed countries - and women face being stigmatized when accessing services. In poorer settings where women face obstacles of cost, domination by a male partner, or obstruction by the extended family to accessing services, the problem is magnified many times over.

The effects of stigma and discrimination against women with HIV/AIDS, and violations of clients' rights to appropriate care at the facility level because of this, were central aspects of virtually all areas of discussion. The dialogue encompassed discriminatory practices of providers, disparaging treatment of HIV-positive women, privacy and confidentiality breaches, and differential access to services and treatment, as well as poorly handled counselling regarding HIV testing, disclosure, and women's pregnancy-related decision-making.

Specific, contextualized examples of the effects of stigma and discrimination are found throughout the various sections of this report, but below are some general observations.

In the experience of ICW participants, women's value as patients in health care settings and the quality of care they receive appear to decrease when they tested positive for HIV. Anxiety about being judged and treated harshly can lead women not to get tested or get into care.

'In our experience- once you test positive your value as a patient depreciate[s] due to combination of reasons including mainly the attitude of health workers.'

'For women living with HIV/AIDS in [X country] the situation is that there is a fear

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