



**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.<sup>1</sup> 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 this<sup>2</sup>.

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<sup>1</sup> 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.

<sup>2</sup> 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>.'<sup>3</sup>

'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.'<sup>4</sup>

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<sup>3</sup> 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.*

<sup>4</sup> 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 of going to get tested for HIV and then being referred to a specialist where often this is where women are stigmatized and discriminated against and judged, and face intrusive questions.'

One contributor, looking more deeply into the roots of stigma, felt more attention should be paid to why people, particularly health care providers, are fearful around people with HIV:

'One of the issues that has not been paid enough attention is the role played by fear in stigma, and that fear has been largely caused by the way we have talked about HIV and AIDS for years and years. In our prevention messages we give the impression that one sexual touch = AIDS and then go on to say that social touching is not dangerous at all. That is a contradiction and so most people



believe that we are telling lies about sexual touching whereas in fact we are telling at least half-truths only about sexual touching. No wonder people are afraid and as said below they do not know, or they do not believe the truth about needle stick injuries etc, because of the way we have talked about sexual touching.

'Therefore, maybe the primary right that has been violated for everyone is the right to accurate and detailed information (not just messages) about the way the virus is transmitted and not transmitted. This would go a long way towards reducing the stigma caused by fear. From a human rights perspective also we should see people as intelligent human beings who are much more likely to make rational decisions if they are given the facts rather than hiding the facts for fear that they will do something risky.'

The contribution below reflects the reality of how pervasive stigma remains; even among those who are themselves involved in working with women, and of how crucial it is to continually reinforce consciousness about these issues with providers and the community:

'There is always stigma in the communities and surprisingly enough even in our own women[']s] organisation. The work of community sensitisation is very big but we must do it. Stigma from health workers is still a problem and it's about time we went back to our health workers, especially the doctors and midwives and PMTCT counsellors, and re-sensitised them.'

## ii) Policies

### *Accountability in HR Laws and Policies*

Even when policies or declarations do address aspects of women's sexual and reproductive health and reproductive rights there is no enforcement mechanism for conventions, agreements and instruments 'adopted' by governments.

'... In my experience these declarations, documents and guidelines are good on paper, but do not necessarily get implemented to do the work they have been meant for - that of improving the situation of the people- in this context- women living with HIV and AIDS.'

'The guidelines and the declaration are adopted and implemented by governments on a voluntary basis. There are no enforcement mechanisms for these. In some cases you see guidelines being adopted by national governments but ending with the phrase 'subject to availability of resources'. This is very worrying. I have seen some of these declarations, like the HIV/AIDS Charter and the Sexual and Reproductive Charter being displayed in health centres, but seeing or witnessing no evidence of staff understanding what it means or living up to any of the calls, promises, and commitments it makes to services users.'

'Many governments have policies on SRHR rotting on their shelves. What we have to do is research which are those governments and then work towards ensuring implementation. And we go into lobbying those who don't have the necessary policies. Some governments have HIV included in adolescents SRHR policies etc. I believe that we need to know for sure and get a strategy in order.'

Moreover, those who adopt the conventions and speak the language of human rights often continue to violate women's rights, albeit subtly, or create policies that are inadequate to the need.

'The other disempowering experience of these international declarations is when they are being discussed and referred to at policy meetings where one would be invited to contribute an HIV positive woman's perspectives on things. You'd sit in the meeting the whole day, listening to people quoting fancy acronyms, which you are not able to attach meaning to, with no one to explain what all the acronym mean and how it relates to you.

'... our government don't have good policies although we have an adolescent health policy which doesn't really address reproductive health in full.'

### *Advocating for Relevant Policy Reform*

Having information on rights and sharing experiences was seen as very important for self- and group advocacy. Clearly, not only must policy makers and service providers understand women's rights and needs, but HIV-positive women must as well, so they are in a stronger position to demand those rights. Indeed, those who are not unified risk having their rights infringed upon.

'I think having information is crucial in any advocacy work, and support from other HIV positive sisters in carrying out our work.'

'Regarding human rights, it's very evident that our rights are violated; there is a law on AIDS and the results we have obtained in that regard pertain to treatment and self-help - if you are organized, they treat you well and if you're not, they treat you like a dog... My experience has been that if we don't fight for others to respect our rights, they will trample on us. We have to fight to live and our experiences will help others survive... I have worked in projects for public defence, in self-help groups and to promote social inclusion of people living with HIV/AIDS. In this way, you help improve the quality of life of each person through programmes of empowerment and training that are very good and help us to live more healthily by changing habits, behavior, [and] attitudes and [acquiring] skills that are very important to live in a healthy way.' [translated from the Spanish]

'... Our only hope, ladies, is to get out there and give it our best to educate our fellow women about their sexual and reproductive rights and also their rights as patients, so that they can educate women patients. If we are waiting for the medical staff to recognize our rights, we are dreaming. It is us who have to make them recognize those rights, it is us who have a responsibility to make them respect and implement these rights.'

A contributor seeking to widen the discussion as to the most effective strategies for promoting a human rights agenda asked this open question:

'Another thing that might be interesting to consider is the tendency of mainstreaming gender and sexual and reproductive rights and health in agendas. How do people feel about this - is it useful or does in reality hide these issues?'

### iii) Services

#### *Provider Attitudes and Discriminatory Practices*

Much of the discussion related to discriminatory practices centred around providers' behaviours within the SRH care setting, and the effects of negative or indifferent attitudes toward women with HIV/AIDS on their willingness to access appropriate care. One contributor, herself a medical provider, had this to say about the casual judgments and violations of privacy among health care personnel in an OB ward:

'Indeed we cannot stress enough the importance of the role of medical staff in the HIV pandemic, particularly in Africa. Women have even failed to follow up counselling services after being traumatised by hospital staff during delivery time. I speak from a witness point of view as I lay in an intensive care ward after a C-section and overheard nurses discuss my neighbour's condition, emphasising that she was positive and really should [not] be having her third child. I wonder what more can be done to improve the attitude of Africa's medical staff.'

The following story, from a contributor doing research in India, suggests that issues of compromised professionalism and lack of basic respect for confidentiality and privacy are major concerns among health workers in general:

'Let me relate my experience visiting a government ARV center in a high-prevalence state of south India: the receptionist asked me if I would like to know more about their counselling techniques. I said yes. So she took me into a counselling room where a young government counselor was speaking with an older man about his status. The receptionist told me he was positive. She told me to sit down. The man looked at me and turned away. The counselor waved me in and told me to sit down saying the man did not mind. I left.'

Other examples suggest that women will sometimes not disclose the true nature of their medical concerns for fear of being treated poorly; or need to be very aggressive with providers in order to get needed treatments. The inevitable result is inadequate care, with clients not being listened to or treated with respect:

'Some women have shared that they go to a clinic because they have an STI, which they want treated but when they get to the clinic they'll say, they have a discharge because they have changed their bath liquid. They'll be knowing very well that if they blame the bath cream for the discharge, they will get a vaginal cream prescription, which is less effective to treat an STI related discharge but they are not disclosing the STI because their fear negative consequences of such disclosure.'

'I have experienced difficulty in accessing Acyclovir in the local clinic and hospitals. Having lived with herpes for a long time I know the symptom of when it is about to manifest on the skin surface. The doctors will not give the treatment until it manifest[s] which in most of the cases it might occur at the weekend; by the time you get the chance to see the doctor, it is useless to take the meds because the virus at this stage takes its course, which is painful and embarrassing. Taking the medication as soon as the symptoms appear stops the development of the sores etc. But the doctors refuse to listen to us. I know my body and I wish that the doctors could understand that. One doctor put me on

prophylaxis; my doctor at CDC (Centers for Disease Control and Prevention) stopped and asked me if I knew how expensive it is costing the hospital to provide me with the drugs. We are told seek medical help as soon as possible but the reality is that the medical team delays the process resulting to conditions of our sexual and reproductive health to get worse.'

'The attitude the doctors have towards patients, that they are illiterate, in most cases patients are not expected to question the doctor...'

Another contributor felt strongly about the need for women to be able to speak frankly with health care providers about their sexuality concerns and needs, chastising those who would blame women for their condition, and flagging the need for SRH-linked programs for those affected by gender-based violence:

'The environment at the healthcare service is not a good one to talk about what happens to you at the home. I think this must change. We should be able to talk about all our bedroom experiences in the health care service centre. Having an STI or an unwanted pregnancy should not be blamed to women as we do not choose to have these; we acquire these under severe violent situations in our homes, from our lovers. There should be programmatic linkages between sexual health and violence against women. I have heard researchers in different meetings reporting that the presence of an STI and or HIV and AIDS suggests that there has been violence. Why are then no programmes which address battered women in the sexual health service?'

#### *Provider Perspective*

Taking the provider perspectives in situations where resources are scarce, infection prevention measures are not in place, or providers are misinformed as to the (relatively minimal) risks of infection, several e-forum participants urged greater attention to the need for providers to be trained in issues related to infection prevention, as well as in supporting human rights in the treatment setting and non-discriminatory care for HIV-positive women.

A moderator posed the issue of provider fears of infection, along with the comments of a health care worker explaining how this arises:

'One complaint often voiced by people living with HIV/AIDS is that they suffer discrimination within the health-care setting: health-care providers are unwilling to treat them. One reason for this undoubtedly lies in negative attitudes that some providers hold; another reason is providers' fears that they may contract the virus themselves while giving care. Many providers are not aware that the risks of infection through a needlestick or sharps accident are extremely low; others even mistakenly think they might get the virus through non-invasive procedures that do not involve any contact with body fluids at all. When protective supplies are unavailable, these fears may be exacerbated. The case cited below is illustrative of this point:

They are human beings, too. They do not have the skills necessary for such care. Moreover, gloves, gowns, goggles, and masks necessary for universal precaution are not readily available in most hospitals. At times, there is even no soap or water to wash hands. Our salaries are very poor, we are short-staffed

and work under stress that increases the risk of accidents and if we had pinpricks and develop HIV, too; no one will take care of us. ...It is not really our faults. We need training; skills and a good working condition to enable us [to] cope with the challenges of caring for these PLWHA." ‘

In response to the issue of provider fears, a contributor emphasized how critical it is to address providers’ anxieties and to acknowledge and support the work they do under challenging circumstances. She also pointed out that people understand risk-taking in highly idiosyncratic ways:

‘We... need to remember that people have different perceptions of the meaning of risk - and tend not to view risk in a rational way (look at the popularity of gambling)... A doctor who would work tirelessly to save lives in an influenza or SARS epidemic - when they are at great risk of infection and death - or rush in to help people wounded in a bomb blast - when there might be another - might still be wary of performing surgery on someone they know has HIV - even though the risk is much smaller.

‘I think it is important to take the fears of health care workers seriously. If they feel that their concerns are understood - and they are provided with accurate information, the means to implement universal precautions, and the chance to take post-exposure prophylaxis if they are inadvertently exposed to a serious needlestick injury from an HIV positive patient - they will be more likely to be reassured and to treat HIV positive patients well. As others have noted, health care professionals are potent generators of stigma - how they behave with patients is noted by all around them. They are also in a strong position to dispel stigma – if they treat patients with HIV with respect, and touch them freely, then others will see this and believe that HIV is not contagious.

‘But the story from Nigeria is very significant - especially the point about short staffing and stress leading to accidents, and the feeling that "if we had pinpricks and develop HIV, too; no one will take care of us." Most health care workers are women - have poor conditions of work - and have a heightened awareness of HIV because they care for so many patients and children with HIV that they cannot save. In noting that health workers often generate stigma we should avoid judging them. Most carry on looking after their patients despite their fears. They deserve appreciation as well as accurate information.’

In this context - acknowledging the present-day potentially greater risks to providers working in sub-optimal conditions - this contributor posed this question to the group:

‘I'd be interested to know whether members of the forum think that, in those many places where antiretroviral therapy is still not readily available, should there perhaps be a policy that infected health care workers should be given priority for treatment (accepting that they may also have the same sexual vulnerabilities to HIV as others)?’

One contributor, a physician, was not particularly sanguine about in-service sexuality or human rights training for health care providers, arguing that until sexual and reproductive health issues are institutionalized –and humanized – in nursing and medical schools (i.e. “pre-service”), progress on this front will be minimal. She pointed out that, while money

is devoted to in-service training and sensitization, medical and nursing schools are “still teaching the same curricula they were 50 years ago,” with no mention of sexuality, adolescent needs, patient rights, human rights to health, and gender equity issues, and minimal attention paid to medical ethics,

'In short, we are not prepared at the universities to deal with the human and social aspects of health and medicine. We are prepared (very well indeed) to deal with technological advances, to recognise the DNA, to know what a virus is and how it disrupts the physiology... we know how many women are dying from maternal mortality in our province BUT we do not know what leads to that, what inequalities and injustices provoked that a 14 years old adolescent lives trading sex with no protection for food; we do not pay attention to a woman that comes with broken bones due to sexual or domestic violence. WE ARE NOT TRAINED FOR THAT. We are trained to deal with the flesh and the bones, but not with the soul and the social factors surrounding this flesh and these bones.

'When are we going to start entering into the male dominated universities and change the curricula and prepare medical doctors and nurses and lawyers and economists with a rights and gender equity (I could say with a HUMAN) approach??? Hope that sooner than later if we want to stop not only the HIV/AIDS epidemic or its consequences, BUT if we want to stop poverty and suffering of poor women and men and adolescents. Count on me if ever this becomes a reality.'

#### *Testing, Counselling and Disclosure*

Testing for HIV is another area that provoked strong feelings; anecdotes attested to the sometimes egregious violations of rights to privacy and information. For some, the decision to test itself is fraught with danger. The researcher looking at domestic violence in India reported her findings that many women in India are beaten or thrown out of their homes if they test HIV-positive.

'Thus in deciding whether to get tested, a woman makes a simple calculus: If I test negative, the very fact that I had the test could result in a beating, and if I test positive I may become a CSW [community sex worker] or die tomorrow at the hands of my husband. So why test? To be effective, HIV/AIDS interventions need to deal with these kinds of realities.'

For women who are tested for HIV, issues of informed consent are paramount; however, these principles are often breached in practice:

'In a workshop with obstetricians and midwives in an Asian country... two women living with HIV share[d] their experiences of what it was like to find out their HIV status in the year 2000. Unfortunately, [neither] receive[d] any pre-test counselling - one woman's family members were told her serostatus before she was and they ended up rejecting both her and her husband (who is also positive). The first she heard about the test was when she was lying on the operating table for a c-section and she overheard the operating room staff comment on her HIV status.'

A moderator cited a recent ICW newsletter article "The Ethics of Pregnancy, Testing and Stigma: The Crisis for HIV Positive Women." [<http://www.icw.org/tiki->

[index.php?page=Publications](#)] to underscore other discriminatory practices and the failure of health care personnel to provide appropriate care and guidance.

"HIV positive women often learn for the first time about their status when they attend an antenatal clinic (ANC) when they are expecting a baby. Suddenly you are told that you have a life-threatening condition, which may also affect your baby. Even worse than this, a woman's husband or in-laws are often told first, in complete violation of her rights. Staff may treat her roughly, as if it is her 'fault' that she is HIV positive. She may be threatened with abortion or sterilisation, whether she wants to have her baby or not, by the very people who should be supporting her in deciding for herself what is best to do next... In the vast majority of cases, it turns out that a woman's husband is also HIV positive. Yet it is assumed – quite illogically and unjustly<sup>5</sup> - that because you were tested first, you must have been the one to bring HIV to the relationship."

One contributor felt strongly that many issues related to current counselling and testing practices need to be re-examined, and that preparation for these programmes is currently inadequate. In particular, issues related to "opting in/opting out" protocols need to be looked at more carefully, and better counselling practices put into place that truly honour the concepts of informed consent:

'I think it's important to prepare carefully before starting to offer VCT to women in the ante-natal clinic. Too often programmes are begun before counsellors have been adequately trained, before the community has been well informed, and before community level supports are in place. The message has been "learn while doing" ... [But, while programmes such as these may take a while to become established], when the adverse consequences for women and their families can be so serious I think we have a duty to be sure that we minimise harm by preparing carefully.

'...The current rhetoric uses terms such as "routine screening", "routine testing", and "opt-out"... The reason I feel that such terms are dangerous is because it is those who are least powerful that are least able to decline to be tested, or to 'opt-out'. Anyone who has worked as a clinician in a developing country knows that the least powerful (especially many women, and the poor, the rural, and the unemployed) are unlikely to disagree openly with anything instructed or requested by a health professional, even though it may not be what they want. They will not 'opt-out' verbally from having the test – but they are likely not to return for the result – or may not seek health care at all if they know it will mean an HIV test. These least powerful people are also those most vulnerable to infection with HIV, and most vulnerable to the devastating effects on livelihood and well-being of discrimination.

'It took a long time to link the words 'voluntary', 'counselling' and 'testing', so that 'VCT' is used everywhere. It is a shame, and dangerous, to let them be unlinked now. Let's advocate for the use of "routine VCT", rather than accepting 'routine testing'. The proponents of 'routine testing' all say they are not talking about mandatory testing - that they mean testing with informed consent - but we know

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<sup>5</sup> It was noted in the article that many of these women were married to older men and had not had sexual relations with anyone else prior to marriage.

that 'opt-out' effectively precludes 'informed consent' from those most vulnerable.'

Some ICW contributors debated the ethics of testing at all. Negative responses to mass testing focus on the disadvantages faced by women in situations of unequal gendered power relations; for example, the assumption that women who have thus far enjoyed very little control over their lives (including their own sexual and reproductive health) can easily participate in voluntary counselling and testing. In addition, without access to treatment testing is seen as quite limited in its use.

'Why are we testing women in the first place? What is the objective? I know that there is some access to care, treatment and support, but in my opinion it is very limited for us to be embarking on mass testing on those grounds.'

'How voluntary is voluntary testing and counselling? Do people have really power to opt out? Health care centres are seen as by most women as places of powerlessness. So does VCT assume that somehow, in a miracle way, this woman, who have very limited ability to negotiate- who has been subjected to subordination all her life, who as a result of her circumstances have very limited self esteem is going to meaningfully participate and decide whether she should be tested or not?'

'Not having access [to MTCT treatment] would make me think twice about being tested, if there was little I could do to prevent transmission [to an infant].'

For one ICW contributor, testing of pregnant women was problematic for philosophical reasons as well –bolstering notions of women as “vectors” for the disease and moving the spotlight away from men’s responsibilities.

'I have concerns for both-taking statistics from ANC mean that men see HIV as a disease for women- reinforcing stigma attached to women because of their very nature of being women- the bad. I think this form of surveillance also shifts the responsibility away from men, coupled with expanded access to male condom. During my days as youth worker at SAYouth Commission-you would hear young men saying- Women have AIDS we do not- as a result we get free condom to protect ourselves from them.'

Others felt that, on balance, testing was still a good idea despite how imperfectly it is conducted, for it provides women with more informed choices. Ideally, both men and women should be tested on an equal basis, and women should receive information and support prior to an actual pregnancy.

'[Even when ARVs are not available] I think the power of VCT is an advantage to women, even if the partner refused to go for testing. The good thing is a woman once she finds out her status, she can still go on to use protection, (the female condom) especially in cases where she suspects that the partner could be wayward and is engaging in affairs with other sexual partners. Out of mass testing, the woman still benefits, because she will make informed choices on whether or not to have a child if she finds out that she is positive. Again, if a woman finds out that she is negative, she may still try to encourage her partner to go for HIV testing and for both to disclose their status and live positively.'



Women are being tested especially in PMTCT programs, to prevent them from passing on the virus to their unborn baby. Knowing one's HIV status, be it for a man or a woman, is one sure way of preventing the further spread of HIV because once a person knows their status, the result is bound to influence behaviour change and also the issue of stigma and discrimination.'

'Whilst I agree with you that being tested for HIV during pregnancy can be traumatic, if a woman is HIV positive, I think it is really important that she knows. This can increase her options, with regard to how to give birth to the baby and to take Nevirapine or not or start other treatments. There are also decisions to make after the birth - breastfeeding or not? In an ideal world, it makes sense to test before women and men decide to have children but it doesn't always work out that way.'

'I think it's best that women receive counselling during pregnancy or even before falling pregnancy and the counselling must include the issues on HIV and AIDS and how women are vulnerable to infection and how they can protect themselves.'

As we have seen, contributors in both fora decried the violations of pregnant women's rights in testing without true consent and/or disclosing results of HIV tests to others without their approval. At the same time, new guidelines are being developed for women during childbirth who do not know their HIV status. A moderator described one of these protocols: testing women in labour without necessarily obtaining their consent, for optimal results in administering ARVs to both the labouring woman and newborn if needed. Responding to the ethical dilemmas posed by this practice, a contributor discussed another protocol being piloted in Tanzania which retains women's right to consent during labour: women are offered the choice of rapid HIV testing and given the opportunity to say no. While the contributor acknowledged this was not as good as ante-natal counselling and testing, she felt this provided an opportunity to catch those women who are HIV-positive who would not otherwise have been tested, and to provide them with nevirapine or other ARVs. She acknowledged that this protocol still fails to reach the many women globally who deliver at home:

'So there is still a frontier left to explore - how can we motivate this segment of women - HIV status unknown, who deliver at home - could rapid testing somehow be shifted to community-based skilled birth attendants who attend home births? Any way to still get timely HIV prophylaxis to newborns who are HIV exposed during home births?'

### *Pregnancy-Related Decision-Making*

As discussed in the previous section, contributors described situations where women testing positive for HIV were judged harshly for being pregnant or wanting children, or even coerced into making decisions about pregnancy that were contrary to their wishes.

'Here in X there are lots of comments - that all of us who are positive should be operated on so we can't have any more children. They don't think about women who have never given birth and who want to be mothers.'

Echoing the above theme, another contributor reacted to rumors of physicians secretly injecting contraceptive hormones into HIV-positive women who keep getting pregnant,

asking pointed questions about HIV-positive women's rights in making their own decisions about pregnancy and childrearing:

'What has become of the "patient's informed decisions"? Our right to make informed choices in our lives as women, our rights to motherhood? We talk of re-infection of the virus, how is the injecting of the contraceptives going to prevent this? The message I hear here is: it is okay, you can have casual sex as long as you do not fall pregnant, we don't want to worry about your unplanned child...'

Aside from the above comments, there was not much dialogue related to decision-making during pregnancy per se. An exception was a series of exchanges on the ICW e-forum, after an HIV-positive woman voiced her desire to have a child, and the conflicting pressures she felt.

'I got married in June 2003. My husband and I are both HIV positive. My husband has two children from his first wife, now deceased. When we got married I did not have a child. I would like to have a child, but my husband does not want to at the moment - he says he is frightened that it will have a bad effect on my health. I want with all my heart to have a child - to experience pregnancy and the joy of motherhood. What should I do?' [translated from the French]

In response, ICW members provided advice, suggestions and support:

Dear X,

'Sorry for what is happening but do not lose hope and do not even get angry to your husband for he is just lacking knowledge. You still deserve with all your heart to have a child, to experience pregnancy moods and motherhood's joy and love your child...

'You and your husband needs to go to the HIV/AIDS-family counsellor who will know how to convince your husband to be flexible with your idea and provide you skills on when you have to get pregnant according to your CD4 counts and your health. [The writer went on to discuss ART, a healthy diet, and caesarean section as an optimal choice.] He/she will then tell you when to breastfeed your child and how to raise your HIV negative adourable child!

'So, what do you think of that .... you have the right of sexual and reproductive health my fellow women and I believe you will be a very good example of what might be happening around your community and how to fight on justice and gender human rights especially on women living with HIV. All the best and good luck!'

Dear X,

'I was touched by your email and I understand your need... I see your husband's struggle of the love he has for you and I guess one of his worst fears being losing you in the process of you having a child. It is possible for HIV positive woman to carry pregnancy without complications as long as you work very closely with your doctor to determine how strong your body immune system is, it is a fact that pregnancy weakens our immune system generally and being HIV positive might make the condition worse.... I believe that communication in your relationship is the key to your answers. Between you and your husband and both of you and your doctor.

'All in all my dear, it is about you, your needs and your health. Put your self first and think what is best for... the whole you. I trust that you will find the answer there, which might not necessarily be the one you want but the best for you and your health.'

### *Experiences of Marginalized Women*

HIV positive women who are also socially marginalized for other reasons - for example, because they are immigrants, are young, inject drugs, are in prison, or are sex workers - face significant barriers in accessing care, treatment and support, due to the additional stigma attached to their specific life situations. Barriers include unwillingness to access existing services for fear of being deported if they are illegal immigrants, and substandard or negligent care given to prisoners, drug users, sex workers and those immigrants who do attempt to use the health care system. The four examples below – of migrants, female prisoners, young women, and injecting drug users - were contributed by an ICW member from Panama:

Migrants fear deportation and do not seek healthcare.

'Women living with HIV/AIDS and migrants have big problems when they go to health services. This is a big obstacle, as if when they are talking to the doctor women say that they are illegal and don't have the correct documents, the doctor simply says that s/he can't give them treatment if that's what they need, although they can get medical attention and medicines for other opportunistic infections. Many foreign women are frightened to seek help because they think they could be deported. The women who use our foundation most to get information are from Dominican Republic and Colombia and who use drugs. When they are diagnosed HIV positive and go to social services, they are asked if they use drugs of any kind, and if they say yes they are not eligible for treatment, because it's considered a wasted investment and that other people could benefit more.'

Female prisoners receive treatment only in advanced stages of illness.

'Women living with HIV/AIDS in prison... rarely get medical attention unless they are in a bad state of health.'

Young women who become pregnant are very vulnerable to manipulation and threatened with sterilisation rather than being given counselling and support. The Panama contributor, who has started a "Mamas Club" support group for young positive women, shared her experiences in working with these young women:

'Often when they are women of 15 to 17 years old, and they are pregnant, doctors violate their rights by telling them they will be operated on so they can't have more children. I have been involved in situations where this has happened, and I try to inform the doctor of the error s/he is making, and to support the young women and seek the best for them.'

Injecting drug users often do not seek treatment out of fear of stigmatisation. Aside from the negative attitudes of service providers who deem them unworthy of care they also fear losing their children.

'Women drug users fall into the silent category for a variety of reasons. If they have children, they might be taken away from them - because of the belief that they are not fit

to be mothers. If they want to become pregnant, they do not have any support. In fact they are advised not to get pregnant. If they do become pregnant (in many countries) they very often are encouraged to have a termination. If they need antiretroviral treatment, they do not get it as it is assumed that, one, they will not comply with adherence and two, it is not worth it to give it to them as they are self destructive, anyway.'

### III. Conclusion: Improving Services, Changing Policies

The many barriers to care identified throughout this report imply myriad gaps in SRH services and policies for HIV-positive women. These include systemic problems such as access, as well as specific gaps in service content and in human rights enforcement. Contributors also offered many recommendations via programme research, advocacy, programme implementation and social action to improve the quality of care and safeguard the human rights of women living with HIV. What follows is a discussion of the major impediments to quality care, concluding with suggestions on how to make changes moving forward.

As the findings on gaps in services and suggestions moving forward are discussed, it is important to reiterate the caveat that the ideas, concerns and recommendations recorded here are often the contribution of one person or a few people, and cannot be generalized from. That being said, we believe they are highly illustrative of the lived experiences of HIV-positive women: the voices are those with experience and insight, whose perspectives can often be confirmed in the academic and grey literature. Even where they cannot be, they are offered as part of the broad spectrum of views to consider, when developing programmes and policies for HIV-positive women.

#### i) Systemic Issues: Access and Resources

This issue of access was alluded to several times, perhaps most strongly emphasized in regard to marginalized populations and their limited access to care. Even where treatment is available, access can be compromised for numerous reasons, such as **cumbersome eligibility systems that thwart ready entrée and pose financial obstacles:**

'In my opinion, [gaining] access to antiretroviral therapy (ART) is a pretty bureaucratic procedure because they wait until the person is in a very bad state to be able to access the treatment. And it involves an innumerable number of laboratory exams that are not yet done at the referral hospital because it is private, so you must see how you can get these exams from the central epidemiological programme which is located [elsewhere]... And if you're not well organized, they tell you it costs a certain amount. (Translated from the Spanish)

**Restrictions on access to care can often be directly traced to discriminatory practices** - although health care workers may be completely unaware of their violations, as with this example from a researcher in India:

'I went to speak to the woman who heads the ARV center. She then told me that her job was to determine who "deserves" treatment. The clinic had been in operation nearly one year, but was giving out only one quarter of their ARV quota. I think there is a long way to go here.'

The issue of accessing care has many dimensions; one very powerful obstacle is the role of internalized stigma among women (and men) with HIV. This can lead to deep feelings of guilt and shame, which in turn can prevent or delay seeking care. The below

illustrates how societal and psychological factors can intertwine among women who have been abused, and of the difficulties this can pose in obtaining SRH services:

'It is difficult to seek sexual health services for all women with HIV; I think it is even more difficult if you are in abusive relationship. Your confidence and sense of self-worth gets flushed down the drain. You are scared to face the world. You are scared to be judged if you go to the clinic with signs of being beaten, in some cases, you think, why even bother, I am worthless anyway, I am leaving it untreated. In some instances you are blaming yourself for the violence which is being directed to you. When you have an STI and marks from being beaten you know that as a woman - young for that matter, you'd take the blame for being beaten, you know that people would be saying, she asked for it or she was beaten for cheating.'

**Thus access is compromised when services don't incorporate outreach interventions to HIV-positive women** tailored to these issues, and when providers fail to respond sensitively and non-judgmentally once women come through the door of their facilities.

Lack of resources did not directly emerge often as an issue, though it was an undercurrent and was perhaps assumed by many contributors. It was mentioned specifically in relation to equipment shortages for providers, leading to compromised infection prevention protocols. In addition, one contributor pointed out that where she lives there are large shortages of qualified laboratory technicians, and that "advocacy for cheaper diagnostic tests is a very big challenge, especially for the most rural areas where no basic tests can be done."

## ii) Gaps in Services: Provider Training, Counselling, Scope of SRH Care

**Provider training on stigma, discrimination, clients' rights and human rights.** The need for provider sensitization to the issues of stigma and discrimination has been discussed as important both for providers already working with HIV-positive clients and as a pre-service essential: that is, focusing on students of medicine, nursing and allied professions so that by the time they enter the workplace, they are aware of the issues and capable of dealing with them. Ultimately, a cultural shift in how medicine, SRH and HIV are studied is needed to institutionalize such pre-service education. Additional suggestions were made for human rights training in relation to clients' rights such as confidentiality and privacy, with a particular focus on disclosure. As one contributor commented about a workshop she attended: 'We talked about how human rights mean that clients also have rights and that all women should be counselled and then told the results directly without results being given to other persons without their permission.' This relates to the need for more counselling services in general, discussed below.

**Counselling services sensitive to the range of needs of HIV-positive women.** Improved quality of counselling came up quite often as a need in a range of contexts: preserving privacy and confidentiality, respecting women's rights to information and to autonomy in disclosure decisions, being supportive of pregnancy-related decision-making, being sensitive to sexuality issues of HIV-positive women – and willingness to talk about them, and emphasizing the "voluntary" in VCT counselling, counselling with truly informed consent.

One e-forum member from Bolivia emphasized the lack of HIV-related information available in confidential settings, especially for young women, and the dearth of attention paid to the psychological needs of women living with HIV. The issue of confidentiality is paramount given the level of stigma she observed in Bolivian society; as she explained, 'The policies are oriented especially to providing medication and attention but not the psychological need.' In addition, the topics of sexual activity and coping with one's family and partner are 'given insufficient attention in policies and programmes.'

***There is a need for more in-depth counselling and follow-up post-disclosure.***

Women risk abandonment, divorce, and/or domestic violence upon revealing a positive HIV status. Since for women, the majority of testing continues to happen in ANC settings, this supports a suggestion, discussed in a later section ("Suggestions Going Forward") to do follow-up research on women in ANC programmes who test positive.

'Most men do not want to take the responsibility once HIV is discovered in the marriage. I have had this experience with group of HIV positive women that I work with. I also went through the same experience. The trend is the same, once HIV is discovered, the blame is put on the woman, and she's abandoned or divorced. For the woman who falls pregnant in that condition, normally the husband is not supportive when it comes to ante-natal care at PMTCT centres. Some men even go to the extent of denying paternity of the baby as they do not want to be associated with a woman who is HIV positive. The woman seeks all these alternatives of preventing her child from getting HIV infection and looking after the pregnancy on her own.'

***Providers should be made aware of the complex psycho-social dynamics in relationships with gender-based violence,*** where the psychological damage to women is considerable, and of the potential effects on HIV transmission. We have already seen how fear of violence influences women's decisions as to whether to test for HIV, as well as how women in abusive relationships are more hesitant to seek care. This is made even more tragic in that these women can be more vulnerable to HIV and STIs, as they are less able to negotiate their sexual activity.

'In my experience, as a woman who's been in violent relationship in the past is that, if the relationship is violent, you are in less able to negotiate safer sex. Also, my experience is that a violent male partner would also be having relationships with other women, as way of hurting you even further, consequently the chances of STI would increase. Also, even if there are chances of succeeding in negotiating safer sex, you would not insist because you fear him leaving for the other woman, thinking may be she is not as 'demanding' as you are-if I refuse giving him flesh to flesh- he'll go and get it from the other woman.'

***Wider Scope of SRH Services.*** Widening the scope of services means offering a greater range of actual services provided. It also implies expanding conventional definitions of what constitutes "sexual and reproductive health services," so that providers will think more broadly about HIV-positive women's needs, services will be more integrated, and referrals and linkages can be strengthened.

***Sexual and reproductive health services for HIV-positive women should incorporate all gynaecological care,*** regardless their relationship to sexual activity or obstetrics. Some reproductive tract infections, for example, are not sexually transmitted.

Regular pap smears are critical for women with HIV/AIDS, as cervical cancer is an opportunistic infection; and breast exams are as important for women living with HIV/AIDS as those who are HIV-negative, but often neglected.

'I wish that part of CDC responsibility to female patients would be to do pap smears on site. Not sending the women off to other clinics which cost them time and money; unfortunately, most women, not understanding the [importance] of the paper they have been given to take to another clinic, they go on with their lives. It is sad that by the time the docs take this seriously is when things are serious and I have seen a good number of HIV positive women die from cancer which should have been detected and stopped.'

***Referrals and linkages to ancillary SRH services not directly provided should be made stronger.*** Strongly emphasized were the needs for screening for gender-based violence and for solid programmatic linkages to appropriate services. One contributor said that it's critical 'to engage women's groups and feminist organizations in supporting HIV-positive women who are victims of gender-based violence.... these groups are absolutely essential: they have been working on issues of domestic violence, female literacy, economic inequality, for years, they know the issues and they have the contacts.'

Additional gaps identified through the e-forum include:

- Lack of exploration of alternatives to biological parenting – such as foster care or adoption – for HIV-positive women desiring children but fearful of the possibility of transmitting infection.
- Related to the above, the lack of support for assisted conception, especially when partners are sero-discordant. Although sperm washing is available in the UK, very few clinics provide it and it is at a cost. Also, not everyone is eligible (e.g., drug users).
- Microbicides are not yet ready for testing on HIV-positive women, and this limits their options.
- Inadequate services that are not comprehensive or rights based for sex workers
- The lack of access to/government subsidization of the “morning after” pill and post-exposure prophylaxis to help rape survivors prevent pregnancy and HIV infection.

### iii) Gaps in Human Rights Documents and Accountability

The major gap discussed related to human rights documents is the lack of a document specific to the rights of HIV-women. While some rights documents have language that applies to women, or to those who are HIV-positive, none directly address the specific issues important to women living with HIV.

Currently, many governments are not being held accountable to the agreements they have signed, and contributors exhorted one another to do activist research on those agreements in order to engage the powers that be to enforce human rights and end discriminatory practices. For more discussion on research and monitoring suggestions, see the section discussing human rights in “Suggestions Going Forward,” below.



## IV. Suggestions Going Forward

Each of the gaps identified above also contains a suggestion for a service or policy change going forward. Additional suggestions were made for research to improve services and advocate more effectively for human rights accountability, and for programme implementation. The ongoing activism of HIV-positive women was also offered as a model for engagement as we move ahead, along with the frustrations at keeping their voices heard.

### i) Research and Follow-up of Women Who Test Positive

A few different contributors emphasized the current lack of information on what happens to women once they test positive – ('... I wonder if anyone has looked at women's ability to negotiate their care post testing positive, which I think takes a lot in terms of self-worth and confidence') - and importance of doing follow-up research.

'One of my concerns is that there have been relatively few examples of studies that have tried to follow up women who have tested positive for HIV during pregnancy or labour to document the impact, positive or negative, on the women and on their families... We need many more reports about what has happened to the women who have tested positive in different settings. We need both qualitative studies and quantitative surveys – but case studies would also help to inform planning. I'd like to urge those with follow up data or stories (especially longer term) to publish or share their findings.'<sup>6</sup>

Among these suggestions was one to specifically track the treatment of young HIV-positive women, to document their progress and use the information for advocacy purposes:

'...We also have to be alert and follow closely how HIV positive women and girls who are teenage mothers are being treated at the health centres or what programmes are initiated because of policy provision. We must fight for an environment which suits young women - those who are expecting but also those who need to access information and there should be no discrimination whatsoever.'

### ii) Addressing Programme Implementation Issues

#### ***Avoid scale-up problems through research and monitoring of pilot programmes.***

The suggestion to do follow-up research on women testing positive in ANC sites had an additional rationale to that of providing support to individual women: learn lessons on

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<sup>6</sup> a) Rebecca Cook provided a reference to a case study designed to be used in training, "Counseling and Caring for an HIV-Positive Woman." In Cook, Dickens and Fathalla, *Reproductive Health and Human Rights: Integrating Medicine, Ethics and Law*, Oxford, 2003. The book is available in Spanish and Portuguese, and is forthcoming in French and Arabic.

b) One study related to these topics was submitted by a Human Rights Watch staffer: Marianne Mollmann's 2004 report, "A Test of Inequality: Discrimination against Women Living with HIV in the Dominican Republic," <http://hrw.org/reports/2004/dr0704/>.

programme implementation and avoid repeating problems when scaling up pilot programmes.

‘...The international pressure to roll out the [PMTCT] intervention has often meant that ante-natal testing has begun without the preparation needed to ensure that women who test positive will be followed up and given support and care... Many countries are now scaling up third prong PMTCT programmes - I think it's very important not to scale up the problems.’

***De-emphasize targeted approaches to HIV prevention and treatment.*** Recognizing that stigma is a powerful barrier to accessing information and care, one researcher found that interventions which avoid targeting specific populations (still often inaccurately referred to as “high-risk groups”) are more likely to be successful. A narrow focus on a presumed high-risk population – such as an intervention educating truck drivers in India to use condoms with sex workers, for example - can miss other theoretically “low-risk” populations, such as the wives they have sex with when they return home.

To the extent that some interventions are targeted – for example, with men in India who have mostly clandestine sex with men in India, of whom the vast majority are married with children – expansion of such programmes would help protect both men and women.

***Improve linkages between donors and service provision.*** Improving communication and understanding between donor organizations and aid workers on the ground is key, as underscored by one researcher’s observations:

‘One of my clearest findings has been that aid workers on the ground - in the town and villages actually working with people - are well aware of most of these problems (such as the problem of increased stigmatization associated with targeting), but that donors in capital cities are not. In India, I asked aid workers if they had sought to bring their findings to their donor organizations. They said yes they had tried, but that donors "had their own agendas" and were not willing to make changes in the programs once they were underway. Indeed, I detected a pervasive and growing antagonism among aid workers on the ground - generally Indian nationals who have been active in the field for many years - towards the donor organizations. Many told me they felt that representatives from the donor offices spent too little time in the field to appreciate the complexity of the problems, and that as a result, funding was not being used in the most effective way.’

Other ideas for programme implementation included:

- Explore how to meet the needs of women in labour who present without knowing their HIV status, without violating their rights.
- Develop protocols for women delivering at home, including administration of HIV prophylaxis to newborns.
- Offering VCT more universally, rather than the current focus on ANC clinics: ‘I think it would be good if people could be offered VCT (not offered a HIV test, but routinely offered counselling about an HIV test, followed by the test if they request it), in many settings - in health care settings, in workplaces, in universities, in prisons, ...next to pharmacies, for example.’

- Providing information to women about HIV counselling and testing, prior to/regardless of pregnancy status, by 'engaging in a vigorous campaign on HIV and AIDS awareness in the religious settings that most women attend almost every week. These will provide a platform to address women on HIV and AIDS, VCT, and any other related issues.'
- Advocating for free medical treatment for HIV+ mothers, particularly in terms of the costs of C-sections, drugs for mother and child after birth, help with the costs of infant formula and continued treatment for mothers after giving birth, for example, ART.
- Involving men in advocacy. For example, in one African country the Positive Men's Union is represented in the executive Committee of the Mamas Club.

### iii) Ensuring Human Rights Accountability

Several contributors from the ICW forum made clear the imperative for research about the status of human rights locally, to develop methods for monitoring and ensuring governmental accountability and enforcement. It is also an organizing tool for strategizing: for with knowledge comes power.

'First of all, we need to build a strong advocacy force amongst ourselves, including the very women we are advocating for. We need to review all the old policies which produce a negative effect... Gathering together all other issues that go with reproductive and sexual rights makes it seem like a better approach. To evaluate these policies could come in the way of research. We can develop tools of monitoring, again involving those concerned and tools which are favourable to them. Let's use our networks as well to come up with these tools.'

Research methods should be participatory, and should not neglect young women:

'Many of the stakeholders involved have to be involved and as you all know we like laying down policies which don't suit young women. This attitude of being older and wiser doesn't work because young women are entitled to reproduction like we are.'

Another contributor suggested that groups can write shadow reports and other communications to Treaty Monitoring Committees, to highlight how rights are violated and which measures are needed to prevent such violations.

Additional ideas for improving human rights for HIV-positive women included these:

- Governments should review 'customary laws, and raise awareness among communities, of harmful cultural practices which infringe on the rights and dignity of HIV-positive women and adolescents.'
- Policies are not just needed that directly address women's reproductive rights but those which protect the more universal human rights of women. Women can only fully realize their reproductive rights if all rights are recognized.

#### **iv) Advocacy and Activism Among HIV-positive Women**

The ICW forum attests to how much HIV-positive women have become organized and socially active in many countries. Among other things, contributors mentioned continued involvement in leading support groups for other HIV-positive women; in workplace advocacy about non-discrimination and gender-based violence; participation in the UN Global Fund for AIDS, TB and Malaria's Country Coordinating Mechanisms (CCMs); and in faith-based outreach and education. This work is not without its frustrations. For example, in Peru, there is one slot on the CCM reserved for an HIV-positive woman; however, in reality there is little meaningful involvement, with virtually no participatory role. Moving forward, HIV-positive women are committed to expanding their influence within communities, and on policies and programmes, through advocacy, research and more central roles in decision-making and educational fora.

## V. Postscript: Living Positively and Making Connections

HIV positive women are often caught in a cycle of needing to care for themselves and other family members while trying to sustain livelihoods that are insecure because of HIV and gender-related stigma and discrimination. ICW members have to cope with these daily realities while at the same time trying to make positive change for positive women at all levels of society. The following story captures not only the many problems and challenges, but also the spirit that HIV positive women around the world continue to show against many odds.

'I am a woman 42 years of age and am living with HIV for the past 17 years. I am a mother of 3 [young adult/teenaged children]. My husband died and left me pregnant with the last born. I have managed to live so far but the journey is not an easy one especially when you live in XXX where there are many challenges in a day. I work at... an organization which deals with prevention programmes for HIV. Our biggest challenge as an organization is funding. I have not had my salary since January 2005 including the rest of the staff. For me it means a lot because I am the sole breadwinner and I take prophylaxis drugs of clyndamicin and fluconazole. For fluconazole we have a free programme in XXX but sometimes you find the drug not available. I have been fortunate enough when I met a friend... who sends me ARV drugs of kaletra and combivir for the past four years when my cd4 count went down to 4. The problem started beginning of April when she said she can only send me one drug- kaletra only- then I began to feel stressed up because I have all these other problems. I love working and working hard but lady luck was not on my side. 2005 we did not have good rains as I have a small field at my rural home which makes life easier for me and my children but alas there is drought and what it means is that we have not food.

'I am a survivor but I have a big mountain to climb every day. I have no house of my own but I managed to buy a piece of land to construct a house, but building materials have skyrocketed. There are so many challenges to climb but I am always positive about life. I live for the day and hope that tomorrow will be different. I am employed as a programme officer and counsellor. I talk about how to survive even when there is no doctor. I teach widows and other vulnerable groups about health eating and alternative therapies e.g. using herbs but what I see in my country is that there is a lot of poverty and it drives women to prostituting for survival. You see why I want to start a group so we can move on with our lives. So many young women talk about sex and relationships and sometimes I have no answers and am also trying to survive. I have many clients, women who feel we have to form a group. This is where I am. Please I need information about microbicides. I love you all and I send my biggest hug and love to everyone in the ICW group. May God Bless you all.'

The above message was cross-posted into the interdisciplinary forum, where a participant from a women's health NGO asked to be put in touch with the woman above to assist her with obtaining needed resources. The connection was made.

## Appendix 1: Questions, SRH For HIV-Positive Women E-Forum

### Human Rights and Legal Issues

#### *Week 1: The impact of human rights on service provision, part 1*

- What human rights concerns (e.g issues of access to services, ensuring informed consent, confidentiality, and non-discrimination) do you face in setting up prevention, treatment and care services for:
  - HIV-positive women who are pregnant?
  - HIV-positive young women and adolescent girls?
  - HIV-positive women who are not pregnant, including post-menopausal women and sterilized women (who tend not to frequent SRH services)?
- What cultural, political or legal barriers impede HIV-positive women's rights to access these services?
- How have international human rights documents or advocacy efforts facilitated access to these services, if at all?
- What accountability mechanisms exist for current human rights agreements? How can we advocate for stronger enforcement of human rights?

#### *Week 2: The impact of human rights on service provision, part 2*

- What human rights concerns (e.g issues of access to services, ensuring informed consent, confidentiality, and non-discrimination) do you face in setting up HIV prevention, treatment and care services for key populations?
- What cultural, political or legal barriers impede HIV-positive women's rights to access these services?
- How have international HR documents or advocacy efforts facilitated access to these services, if at all?
- What accountability mechanisms exist for them? How can we advocate for stronger enforcement of human rights?

#### *Week 3: The role of human rights and human rights documents*

- What role can/should human rights ideally play in furthering HIV-positive women's access to sexual and reproductive health services? Are there specific examples we (governments, human rights organizations, civil society groups and NGOs, HIV/AIDS advocates and researchers) can point to of using human rights concepts to successfully influence services and programme policies? (One example would be to take the government to court to get access to antiretroviral treatment; another would be to highlight

discrimination against HIV-positive women in an NGO “shadow report” regarding governmental compliance in implementing an international treaty like CEDAW.)

- What role can/should international documents ideally play in furthering HIV-positive women’s access to sexual and reproductive health services? (Examples include the *Barcelona Bill of Rights*, *International Guidelines on HIV/AIDS and Human Rights*, the *ICPD Program of Action*, the *Beijing Declaration and Platform of Action from the 4<sup>th</sup> World Conference on Women*). Have any international or national human rights documents “trickled down” to have impact on the ground?

#### *Week 4: Lessons learned and directions forward*

- What are the key lessons learned about how advocacy and a rights-based approach can improve access and prevention, treatment and care services for HIV-positive women, including young women? What should the roles of governments, human rights organizations, civil society groups and NGOs, HIV/AIDS advocates, and researchers be in addressing these needs?
- Which human rights issues have not been covered that should be? How can we best advocate for those? Do we need more treaties and agreements than those currently in place?
- What would the ideal policy framework incorporating human rights guidelines for HIV-AIDS services look like at a country level?

### **Programme Services and Policies**

Week 1: Sexual and reproductive health services for HIV-positive women: issues of concern and obstacles to care

- Which sexual and reproductive health issues of concern to women living with HIV, including young women, do you think are neglected or given insufficient attention in policies and programmes?
- What obstacles do you see or encounter in ensuring that HIV-positive women, including young women, have access to reproductive health services?

*Week 2: Sexual and reproductive health services for HIV-positive women: programme successes and ways to overcome obstacles to care*

- What is working well regarding sexual and reproductive health services for HIV-positive women, including young women?
- Are there programme models that are currently solving problems of access and if so, what are they?
- What other potential solutions might there be to overcoming obstacles to access and appropriate care?



*Week 3: Technical resources and program policies and guidelines*

- Which technical resources would you need to improve sexual and reproductive health policies for women with HIV/AIDS, including young women? For example, national policy guidelines, clinical protocols for programme managers and providers, job aids, manuals or other written materials? On-site or off-site trainings/workshops? (If so, in which topic areas?) Equipment/supplies? Introduction/enhancement of quality improvement approaches (e.g. COPE, Appreciative Inquiry, etc.)? Other kinds of resources?
- How can we ensure that services and programme policies are based on a gender-equitable and human rights approach – specifically, at the level of the institution/program and provider?

*Week 4: Ensuring the participation of HIV-positive women and other programme priorities*

- What concrete steps can we take to ensure that HIV-positive women, including young women, are involved in planning, implementing and evaluating sexual and reproductive health services, including programme policies and research?
- If you had to choose, what would be your top three priorities regarding programme implementation and associated programme policies to increase access to sexual and reproductive health services for HIV-positive women? Of these priorities, which are the most important things to tackle in the short- and medium-term? Which for the long-term?