Bibliography No. 18

Women and Girls living with HIV/AIDS: Overview and Annotated Bibliography

Report prepared at the request of Irish Aid by BRIDGE in collaboration with the International Community of Women Living with HIV and AIDS (ICW)

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BRIDGE supports gender advocacy and mainstreaming efforts of policymakers and practitioners by bridging the gaps between theory, policy and practice with accessible and diverse gender information. BRIDGE was set up in 1992 as a specialised gender and development research and information service within the Institute of Development Studies (IDS), United Kingdom (UK). This was on the initiative of the Development Assistance Committee of the Organisation for Economic Co-operation and Development (OECD/DAC) Working Party on Gender Equality (now the Gendernet). BRIDGE is one of a family of knowledge services from IDS.

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ICW was established as a response to the desperate lack of support, information and services available to women living with HIV worldwide and the lack of influence and input they had on policy development. ICW is now the only international network of HIV positive women with over 5000 members in 134 countries.
Our vision is a world where all HIV positive women:

- Have a respected and meaningful involvement at all political levels where decisions that affect our lives are being made;
- Have full access to care and treatment;
- Enjoy full rights irrespective of our culture, age, religion, sexuality, social or economic status/class and race.

Contact details for both organisations are under section three: networking and contact details, at the end of the report.

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Section one: an overview

1 Introduction

The number of people living with HIV has now reached almost 40 million (UNAIDS/WHO 2006). Women and girls are especially vulnerable to HIV infection due to a host of biological, social, cultural and economic reasons, including women's entrenched social and economic inequality within sexual relationships and marriage. Globally there were 17.7 million women living with HIV in 2006 – an increase of over one million compared with 2004. In sub-Saharan Africa, almost 60 percent of people living with HIV/AIDS in 2006 were women (ibid).

HIV/AIDS is not only driven by gender inequality, it also entrenches gender inequality (Tallis 2002) leaving women more vulnerable than men to its impact. Women in many regions cannot own or inherit property or land, and have limited access to income and resources. Even women who know their legal rights may not have access to independent legal support (ICW 2004d). Women's unequal social, economic, and legal status is increased by a positive HIV status, and vice versa (ibid). Violations of women's social, economic, and legal rights in turn prohibit their ability to seek care, treatment and support, and protect their sexual and reproductive health and rights.

Women and girls, including those who are themselves HIV positive, also bear the physical and psychological burden of HIV and AIDS care. Women thus carry a 'triple jeopardy' of AIDS: as people infected with HIV, as mothers of children infected, and as carers of partners, parents or orphans with AIDS (Paxton and Welbourn 2004). When women care for others their labour is lost, which has a major impact on their own well-being and on that of the household.

In many contexts, social and cultural values surrounding the importance of female purity mean that women and girls living with HIV and AIDS are subject to greater discrimination than men. 'Good' women are expected to remain virgins until marriage. For men, by contrast, multiple sexual partners and sex outside of, and prior to, marriage is generally accepted and often encouraged. These sexual double standards mean that it is women who are generally blamed for spreading HIV – by women as well as men – and are labelled 'promiscuous' or 'vectors of disease'. The fact that women can infect their babies through pregnancy or breastfeeding intensifies the stigma attached to them as women (VSO-RAISA 2004). Socially marginalised groups – such as sex workers, drug users, prisoners and migrants – face additional stigma. In other cases, however, it is men who are seen as perpetrators of HIV and women as victims (ibid).

Where women are blamed, this can lead to heightened levels of sexual and domestic violence; abandonment by families and communities; forced abortion or sterilisation; dismissal from employment; and loss of livelihood opportunities. This kind of extreme discrimination, especially when combined with heavy domestic responsibilities and restrictions on access to resources, presents a powerful barrier to positive women seeking care, treatment and support for HIV and AIDS – or even to getting tested in the first place.

Yet too often, HIV interventions are not adapted to positive women's realities, leaving them at a disadvantage when it comes to coping with HIV and AIDS. For the epidemic to be tackled effectively, the valuable skills, insights, and accumulated experiences of women and girls living with HIV and AIDS must be taken seriously by policy-makers. Their expertise can be a central force in tackling the epidemic, provided that others are prepared to listen and act on this knowledge (ICW 2004f).

2 Issues around care, treatment and support

2.1 Stigma, rejection and violence

The number of people in low- and middle-income countries receiving treatment for HIV more than tripled between 2003 and 2005, from 400,000 to 1.3 million (UNAIDS/WHO 2006). With the expansion of access to anti-retroviral treatment (ART), HIV positive women and men are more able to live long, fulfilling lives than ever before.

> 'In the future I want to continue living positively to the best of my abilities.'
>
> (Sheerin, from Iran, IPPF/ICW 2004)

Yet gender inequalities can constrain women's access to care, treatment and support. At the root of barriers to care are the sexual double standards which result in women more than men being stigmatised for being HIV positive. This is exacerbated by the fact that women tend to be the first member of a family to be tested for HIV through ante-natal testing – sometimes without their informed consent – and may subsequently be blamed for bringing HIV into the family. This can result in rejection or violence towards women from their spouse or in-laws (Paxton and Welbourn 2004).

Violence, or the fear of violence, means that the decision to get tested for HIV in the first place is fraught with danger, as the quote below attests.

> '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 die tomorrow at the hands of my husband. So why test?'
>
> (Researcher in India, EngenderHealth et al 2006:14)

Internalised stigma may also undermine women's confidence to leave or confront an abusive situation, and is a powerful obstacle to accessing care.

> 'It is difficult to seek sexual health services for all women with HIV; I think it is even more difficult if you are in an abusive relationship. Your confidence and sense of self-worth gets flushed down the drain.'
>
> (Woman from South Africa, EngenderHealth et al 2006:22)

Lesbians, bisexual women, and transgender persons, as well as injecting drug users, prisoners, migrants and sex workers, are particularly vulnerable to human rights violations, including violence, because of judgemental attitudes in society. If they are also HIV positive, they may experience additional stigma.

> 'It's more easy to say I am a recovering addict because it's like saying, 'I been naughty once but I am ok now', than to say I have HIV. Because when you say HIV, Wow!! People they judge you, straight away, it's like, oh my God!'
>
> (HIV positive women, UK, ICW forthcoming)

2.2 Testing, diagnosis and disclosure

Over the past two years there has been increasing movement away from opt-in HIV testing, towards service provider initiated, routine HIV tests, where the emphasis is on the service user to opt-out. This move follows joint UNAIDS and World Health Organization guidance in 2004. While knowing one's status can sometimes enable women and men to better protect their health and that of their partners, the move towards opt-out testing is highly problematic in contexts where inequality and HIV-related stigma make disclosure a life threatening prospect; women and men have limited access to care, treatment and support; women and men are not in a position to decide for themselves whether they want to be tested; and stigma and discrimination from health care providers, in the work place and elsewhere, make asserting one's rights impossible (ICW 2006b).

> 'Do people really have the power to opt out of having a test at health centres, particularly as health care centres are seen as by most women as places of powerlessness? Routine testing assumes, that somehow a woman, who may have very limited ability to negotiate and who has been subjected to subordination all her life, who as a result of her circumstances may have very limited self esteem, is going to meaningfully participate and decide whether she should be tested or not.'
>
> (ICW, 2006b)

For young women it may be especially difficult to opt-out:

> 'You can't opt out. When I got pregnant and had HIV at 16 I only knew my school and local community. …. I knew nothing. How could I know what to ask for at the clinic?'
>
> (ICW member from South Africa, in Merkel 2006)

Moreover, the current drive to test as many people as possible for HIV often ignores the lived complexities of women's – and men's – lives, in which knowing one's status does not necessarily equate with being able to act on that knowledge to improve one's well-being and that of one's family (Exchange 2006). Informed consent must be a pre-requisite to testing and treatment for HIV/AIDS, and pre-test counselling should be an integral part of every woman's decision to learn her HIV status. Much preparation is needed to ensure that women can cope with the consequences of a positive test result – particularly if they are married and have always been faithful to their partner. Respect for an individual's right to choose whether or not to be tested is paramount. This requires the provision of non-judgmental information and support so that they can make more informed decisions about testing, child bearing and rearing (ICW, 2006b).

The current emphasis by the World Health Organization on testing in antenatal clinics (ANCs) is problematic because it reinforces the view that women bring HIV into the family. Disturbingly the highest reported rates of disclosure-related violence are among women who test for HIV in the context of antenatal care (ibid). The focus on testing in antenatal care or childbirth settings further entrenches the perception among women that the primary objective in testing is to protect the health of the infant, rather than also being for the benefit of the women themselves. Moreover, if testing is available

primarily through antenatal services there is a real risk that women who are not pregnant will not be reached.

Targeting antenatal clinics also shifts the responsibility away from men to get tested. When combined with the prevalent belief in many cultures that 'real men' do not get sick, this means that men tend not to get tested for HIV (Esplen 2006). This has devastating consequences, both for men themselves and for their wives or partners. In response, many groups are working with men who are living with HIV/AIDS, to encourage them to get involved in HIV prevention and care – for themselves, their families and their communities. For example, Positive Men's Union (POMU) in Uganda organises community groups made up of HIV positive men to create awareness about testing, and sets up support groups to enable HIV positive men to share experiences (Barker and Ricardo 2005, in Esplen 2006). In general, however, the sexual health concerns of men living with HIV/AIDS are frequently neglected in research and programme efforts, and they often lack information on how to lead a healthy sex life (IPPF, 2005). Acknowledging and responding to the specific sexual and reproductive health needs of HIV positive men as well as HIV positive women is vital if we are to make progress on tackling the epidemic.

For women who do get tested and receive a positive diagnosis, the decision of whether or not to disclose their status to partners or other family members, including children, is hard to make. Decisions around disclosure are multiple: who to tell (family, friends, children, colleagues, teachers, the Church), when to tell, and how to tell. Sometimes reactions can be supportive:

> 'It has brought my family and friends closer together and showed me the strength my husband has.'
>
> (HIV positive woman, ICW 1999:8)

In other cases, women find themselves judged for being HIV positive. Many women fear disclosure due to the threat of violence or abandonment by partners, especially in contexts where women have little or no legal or financial standing. This fear is a potent barrier to accessing treatment, especially where women may have to ask their husband's permission to make or pay for the journey. The result is that many women only seek help at the last minute when they are already very ill (ICW and GCWA 2004b). Moreover, anxiety around disclosure does not necessarily diminish with time – even if someone has disclosed to close family and friends there is always the daunting question of when to tell potential future partners, friends, colleagues, employers.

Unfortunately, for some positive women, the choice of whether or not to disclose may be out of their control, either because their actions may signal their status – accessing HIV-related services for example, or visibly suffering the side-effects of ART – or as a result of breaches of confidentiality by indiscreet family members or health workers. In Mumbai, India, for example, it was reported that health-care workers often disclosed a woman's HIV positive diagnosis to her husband in the belief that the woman herself will not understand (Center for Reproductive Rights 2005). The possibility that their status will be made public without their consent understandably strongly discourages women from

obtaining an HIV test, seeking necessary treatment, or being open about their HIV status. Such breaches of confidentiality also constitute a severe infringement of women's human rights.

A recent participatory ICW project researching services for HIV positive drug/alcohol using women living in London, UK, revealed that many of the women had concerns about disclosing their HIV status and drug use to existing or new partners (ICW forthcoming). In fact, ex and existing partners tended to display a good level of support, but the fear and expectation of rejection was often intense. For HIV positive women who are also injecting drug users, revealing drug use and co-infections is an additional worry. Disclosing drug use or a positive HIV status to one's children is especially difficult for many women, due to concerns about possible negative or fearful reactions, and about the impact on the children's lives.

> 'I had a son, he died last year. When he reached a certain age he was telling me, why? How can you explain to him? Well he knew. I did tell him when he was 12 that he was HIV positive. But then you know its like 'mom, where did I get it from?' 'Ah, from me!' and it was really painful. I love you so much my son – I am sorry, I didn't want, I didn't want you to be sick, and its not only sick, its bad. Can you imagine?'
>
> (HIV positive woman drug user, UK, ICW forthcoming)

2.3 Constraints on access to services

It is clear that the situation is complicated and simply increasing the availability of treatment may not guarantee that women will be able to access such treatment. In Zambia, for example, the Government dramatically reduced the monthly cost of ART from 64 dollars to eight dollars per month. Given that well over half of the Zambians living with HIV/AIDS are women, officials expected to see a majority of women receiving ART. Instead men showed up in far higher numbers than women. In one rural town, of the 40 people on ART, only three were women (UNAIDS/UNFPA/UNIFEM 2004).

The low take-up of treatment by HIV positive women in Zambia, as elsewhere, is a result of the gendered barriers that positive women face in accessing care, treatment and support services. Women's entrenched economic and social inequality within their relationships with men can constrain their ability to access services or abide by the advice given to them by health care workers. The costs of transport to clinics, coupled with the time lost from work or caring responsibilities, as well as the costs associated with childcare, present severe obstacles to women's ability to access treatment. These barriers are more severe for women than men because women are often financially dependent on men. Women's lack of decision-making power and the constraints on their mobility – especially in the Middle East and parts of Asia – mean that they may have to obtain permission in order to seek health care or account for their time to their husband or other family members (ICW 2004b). This is especially difficult if they have not disclosed their HIV status.

Socially marginalised groups, such as immigrants, sex workers, injecting drug users, and prisoners, face particular barriers in accessing services due to the dual discrimination they face as a result of

their specific life situations and their HIV positive status. For example, drug users face double discrimination when HIV positive for those two facts alone – and triple discrimination when female.

> 'Within medical services you always got treated very differently. I suppose they never trusted you so they always treated you like a bit of shit on the bottom of their shoe pretty much.'
>
> (HIV positive woman drug user, ICW forthcoming)

The assumption by many health workers and others that women drug users are involved in commercial sex creates an additional layer of stigma, making it very difficult to access information, treatment and support. In Asia, discrimination against sex workers is so strong that many HIV positive women will not go to a reproductive health clinic for fear of being labelled a sex worker (Paxton and Welbourn 2004). It should be noted, however, that HIV positive men also face gendered barriers to accessing treatment. Men often feel the need to publicly demonstrate that they are 'real men' through taking risks, making it difficult to seek support or attend health clinics which are often seen as 'women's spaces' (Esplen 2006).

2.4 Constraints on adhering to treatment

Even among women who are able to access health clinics, fear of disclosing a positive diagnosis can interfere with their ability to maintain adherence to antiretroviral therapy, and may prohibit them from adhering to prevention of mother-to-child transmission (PMTCT) programmes for fear that using alternative feeding options (rather than breastfeeding) will reveal their positive status.

> 'If you start using milk powder everyone will know you must be HIV positive. If you demand condom use, to stop repeated exposure, he will either hit you or just go off and have sex somewhere else and likely bring back other infections. So you just go on having unprotected sex and breast feeding, even though you know you are doing exactly what they tell you you mustn't do…'
>
> (ICW members from South Africa and Swaziland, Exchange, Autumn 2006:3)

Women living with HIV/AIDS may also be deterred from returning to health clinics by the judgemental attitudes of health workers, who sometimes deny women the opportunity to give informed consent to HIV testing and treatment, violate their confidentiality, treat them with disrespect, deny them services, or push them to access services without providing comprehensive information about alternatives. Health workers sometimes bluntly refuse to care for HIV patients – refusing to let them access clean water, stretchers, waiting rooms, seats, food or even toilets. Directive counselling on contraceptive methods is also common, and positive women often face pressure to have an abortion or sterilisation.

Poor quality services, when combined with having to deal with bureaucracy and long queues, and being at the mercy of everyone from the receptionist, to the ambulance driver, to the pharmacist, to the doctors and nurses, means that accessing and adhering to treatment can be an exhausting, humiliating and traumatic process. Without adequate counselling, treatment and morale is hard to maintain, especially as the side-effects of ART can be severe (ICW 2004b). Changes in body shape is

a common side-effect. This can be severely distressing for women, causing some to hide away (Paxton and Welbourn 2004). Studies in Brazil and South Africa show that intensive counselling, along with support from other HIV positive patients, makes it more likely that AIDS patients will adhere to treatment regimes (UNAIDS/UNFPA/UNIFEM 2004).

Poor nutrition and a lack of basic needs present another major obstacle to adherence. Women who are unable to provide food for their families may feel pressure to sell their medications on the black market (ICW 2006). If a woman's relatives are not on treatment she may feel compelled to share her treatment; in other cases she may be forced to hand over her medications to a male partner or relative (ibid). In contexts where poverty limits the amount of food available and where women are the last to eat, it is practically impossible for them to adhere to ART without additional support, especially since some medicines must be taken with food (see http://www.aidsmap.com/en/docs/B7F81F5E-202C-483C-863F-8A4B54314E3D.asp).

> 'A 44-year-old woman in rural Tanzania who was on antiretroviral treatment had to sell them in order to get some money to take care of the grandchildren living with her in her small home. All of her 13 children had died from AIDS-related illnesses…Of her 14 grandchildren, she takes care of three under the age of five. She thinks eight of the children may be HIV positive as they are not that well. She was only able to provide one meal a day in the afternoon, which consisted of porridge with salt, as that is what she could afford. After she had been on treatment for two months, she started selling her antiretrovirals to HIV positive people who did not want to get medications at the clinic due to stigma. When she joined a group for people living with HIV approximately a year later, they counselled her to stop selling her antiretrovirals and instead to go back on treatment. The group sometimes provides her with food and other important needs.'
>
> (ICW 2006)

2.5 The burden of care

As shown by the quote above, the physical and psychological burden of HIV/AIDS care, which falls heavily on women – often young girls or grandmothers – persistently undermines the resilience of positive women to the consequences of HIV/AIDS, and makes adherence to treatment especially difficult. As the AIDS epidemic leaves growing numbers of children orphaned, women's unpaid work burdens are increasing. In addition to lost opportunities and income (see the section on 'livelihoods' below), many carers experience high levels of stress and exhaustion which significantly impact upon their well-being, especially if they are HIV positive. A rural woman interviewed in Southern Africa estimated that it took 24 buckets of water a day, fetched by hand, to care for a family member who was dying of AIDS – water to wash the clothes, the sheets and the patient after regular bouts of diarrhoea (UNAIDS/UNFPA/UNIFEM 2004). Girls who have lost their parents to AIDS and who are also HIV positive are especially vulnerable, having to cope with their own ill-health on top of caring for their siblings and managing the household (ICW 2004g).

An important step to alleviate the burden of care and support borne by women is to challenge rigid ideas about masculinity which disassociate men from caring roles. It is essential that interventions seek to engage men in childcare and domestic chores and encourage fathers and husbands to play a more active role in caring for and safeguarding their children's futures (Esplen 2006). For example, the PAPAI Institute in Brazil has set up an Adolescent Father's Support Programme which provides information to help young men take on responsibility for their own sexuality and its consequences (ibid).

2.6 Understanding and overcoming these barriers

HIV positive women and girls are best placed to understand these barriers, and to design and deliver better ways of making treatment available to women living with HIV and AIDS. One important step is to train and employ HIV positive women and girls, and positive women's organisations, to promote and distribute ART – although such work must be remunerated and not simply another burden (ICW 2004b). Another is to provide mobile and decentralised treatment distribution, rather than limiting treatment to antenatal clinics in urban areas. This point was emphasised by HIV positive women in Tanzania during a treatment mapping carried out by ICW in 2006. The women identified better transport options and health facilities near villages as essential to improving access to treatment, care and support services. Protecting confidentiality becomes even more critical when services are decentralised to the community level, however.

The complexities of women's everyday realities require holistic approaches to treatment, which go beyond simply providing ART. Priorities include ensuring better monitoring of HIV progression, treatment adherence, ART side-effects and resistance; promoting improved nutrition and income generation opportunities for positive women, and ensuring that women are able to access appropriate screening, prevention and treatment for opportunistic infections and HIV-related conditions such as cervical cancer (ICW 2004b). In addition, programmes should provide psycho-social support and recognise the terrible trauma resulting from so many deaths – especially for women, the primary carers.

Health clinics are also a useful entry point for identifying and responding to women who experience violence as a consequence of their HIV status. Health staff working in HIV services and domestic violence should be trained in both areas to sensitise providers to the interconnections between the two epidemics (UNFPA/WHO 2006). It is also essential to revise the nursing and medical school curricula so that they go beyond health issues – to facilitate understanding of the wider context of positive women's lives – including issues around stigma and discrimination. The need to respect the human rights of HIV positive women should be a core component of the curricula.

Positive women's support groups are also hugely important – in helping women to come to terms with a positive diagnosis, deal with decisions about disclosure, think through their sexual and reproductive health options, and explore issues around care and treatment (Bell, E., Mthembu, P., and O'Sullivan, S., paper forthcoming). Positive women's networks can play a key role in advocating for improvements to treatment, care and support for women and girls living with HIV/AIDS. In August 2005, for example,

the Argentinean branch of ICW backed two of its members in taking the national Ministry of Health to court for failing to guarantee the quality of the AIDS drugs it distributes (ICW newsletter 31, 2005). They were successful!

3 Sexual and reproductive health and rights

3.1 The right to have sex; the right to refuse sex

> 'We must encourage [women] to rekindle their desire without fear or guilt.'
>
> (Masi, South Africa, IPPF/ICW 2004: 20-21)

For many women, a positive HIV diagnosis leads to changes in the way they experience their sexuality. Yet women do not stop having sexual feelings because of a positive diagnosis. Many HIV positive women continue to have sexual relationships and desires; others choose abstinence because they find it empowering. In some cases, women choose abstinence due to feelings of shame, guilt, or the internalisation of stigma; through fear of infecting others; or because of the negative associations with sex that an HIV-positive diagnosis may result in (Exchange 2006). Still others have abstinence enforced upon them (ibid). What is imperative is that women, negative and positive, are given the freedom to engage in sexual relationships if they wish, and to say no if they don't, without facing judgement from others. All women should be able to exercise their right to choose when, how, why and with whom to have sex (ibid).

3.2 Contraception and safer sex

Health care services must engage with the reality that many women living with HIV and AIDS continue to have sexual relationships, whether through desire or necessity. This presents certain challenges. People living with HIV may have weaker immune systems than people who are HIV negative and are therefore biologically more susceptible to contracting sexually transmitted infections (STIs) (Guttmacher Institute 2006). Evidence also suggests that they are at risk of becoming reinfected with another strain of HIV, potentially accelerating the spread of the disease (ibid). Women (and men) living with HIV/AIDS thus require increased access to HIV prevention services and accurate information to guard against unwanted pregnancy; prevent them from acquiring or transmitting STIs – including HIV – to uninfected sexual partners; and to reduce the risk of re-infection with a different strain of HIV.

Family planning clinics have a vital role to play in making information available to support women in making contraceptive choices and seeking safer sex. Information should be accurate and non-judgemental, as well as being easy to ask for, easy to find, easy to understand and in people's own languages (IPPF/ICW 2004). Ensuring access to information can be difficult, however, because of the value placed on women's innocence in many societies. This prohibits women and girls, including those living with HIV, from seeking information about their sexual and reproductive health and rights. This is exacerbated by a lack of scientific research on HIV positive women's sexual and reproductive health needs.

Information about sex can be especially hard to access as an HIV positive woman (ICW 2004a). In some cases, women living with HIV are denied information about safer sex because it is believed that they should not be having sex. This is particularly common in the case of young HIV positive women and girls. In other cases, women and girls are given misleading information or coerced into accepting certain types of contraception. For example, women in Lesotho and Namibia reported that

their access to ART was dependent on their use of hormonal injections or IUDs (intrauterine device) – both of which are doctor-controlled methods of birth control – because it was believed that as HIV positive women, they should not get pregnant (Novib 2006). This is a fundamental violation of women's sexual and reproductive rights. Moreover, the coercion to use a doctor controlled contraceptive method may undermine their ability to negotiate dual protection methods, such as condoms, that would protect them from STIs.

Instead, positive women and girls must be supported in choosing a contraceptive method that is suited to their needs. These needs may change over time, depending on the stage of the disease, their treatment situation, as well as their lifestyle and personal desires (UNFPA/WHO 2006). Contraceptive methods which provide women with 'dual protection' from unwanted pregnancy and STIs (including other strains of HIV) are especially important for women who are HIV positive, and should be promoted and provided by all health clinics. When used consistently and correctly, both male and female condoms are highly effective in protecting against pregnancy and against STIs. With perfect use, male condoms have been proved to be 98 percent effective and female condoms 95 percent (UNFPA/WHO 2006). Condoms also offer protection against reinfection with HIV.

Having access to condoms does not mean that women will necessarily be able to negotiate their use, however. Even when women are aware of the risks involved in having unprotected sex, they may be reluctant to demand the use of condoms for fear that this will reveal their positive status or imply that they have been unfaithful. Helping young girls and women – positive and negative – to acquire the communication and assertiveness skills needed to negotiate safer, more pleasurable sex should also be an integral part of any sexual health programme. Promoting access to equal employment opportunities and productive assets is equally important – giving women a firmer basis upon which to assert their sexual and reproductive rights.

Since contemporary gender roles confer on men the power to influence and often determine the sexual and reproductive health choices made by women, sexual health programmes must foster constructive male involvement in sexual and reproductive health and rights through programmes such as EngenderHealth's Men as Partners programme (MAP) in South Africa. Programmes also have a role to play in challenging men's physical, social, legal, economic and medical control over women's lives. Initiatives should help men to understand the oppressive effects of gender inequality on women and men, while also talking to them about the responsibilities they have because of their privileges to take actions in ways that women usually cannot (Greig 2005, in Esplen 2006).

It is equally crucial that women of all ages are able to access a range of female-controlled barrier methods. Female condoms have the potential to make a crucially important contribution to protecting HIV positive women's sexuality, as many women feel more in control during sex when using the female condom (although it still requires a degree of negotiation with male partners) (Welbourn 2006). Limited access and high costs constitute major barriers to the use of the female condom however, in industrialised countries as in others. Also promising is the current research into the development of microbicides (a substance that can be applied to the vagina before having sex to reduce the risk of HIV or STIs). Microbicides, once developed, will be able to be applied without a partner's knowledge,

enabling women to protect themselves and their partners in situations where negotiating safer sex is difficult or impossible. However, it is essential that positive women are themselves involved in microbicide research, development and advocacy – currently the focus is on developing a microbicide for negative women.

3.3 Access to safe abortion

Even among women who are able to access contraceptives and negotiate their use, many women with HIV may have and seek to end an unplanned pregnancy. When performed by qualified professionals in sanitary conditions, abortion is considered safe for HIV positive women. However, unsafe abortion carries particular risks for women who are HIV positive, due to their increased risk of infection or haemorrhage (heavy bleeding) (Guttmacher Institute 2006). Particular attention needs to be given to ensuring that HIV positive women know where safe, legal abortion is available, understand the abortion procedures being provided and their expected side effects, and are aware of the risks of undergoing unsafe abortions (UNFPA/WHO 2006). Ensuring that health care providers are equipped to prevent themselves getting HIV is also crucial.

3.4 Pregnancy and childbearing

> 'As a positive woman, people say you have no business becoming pregnant and a single positive pregnant woman is treated worse than a criminal in the health centres.'
>
> (Rolake, Nigeria, IPPF/ICW 2004:10-11)

> 'My son, Kiril, is 14 months old. Three HIV tests have shown he is negative which makes me very happy.'
>
> (Tanya, Ukraine, IPPF/ICW 2004:8-9)

> 'I am criticised for having a daughter who is HIV positive. Nothing in the world would make me miss the experience of having her.'
>
> (Rosa, Honduras, IPPF/ICW 2004:18-19)

While HIV-positive women have the right to safe termination of pregnancy, they also have the right not to be forced into termination of pregnancy or sterilisation. For many women the desire to experience parenthood is central to what it means to be human and is integral to their social identity. Having children is also an important source of security in old age, and may help women fight the dehumanising effects of living with HIV (Guttmacher Institute 2006). In many societies, a women's status greatly improves if she becomes a mother (Paxton and Welbourn 2004). For these reasons, some HIV positive women – especially young women who do not yet have children – have a strong desire to become mothers.

Positive women often have limited reproductive choices however, as decisions may be made for them by their husband, in-laws or health care staff. HIV positive women often get caught between pressures

from health workers not to have children, and pressures from family members to have children. In cases where women are unable to disclose their status to family members, or where a woman has no children, or has only girls, pressures on women to have children are likely to be especially acute.

> 'I have five children and am expected to have another because I do not have a son. I went to the hospital to be sterilised. They wanted the husband's consent, but he wouldn't as he did not have a boy child.'
>
> (Positive woman, Merkel 2006)

In other cases, positive women face judgemental attitudes from health care workers who believe that they should not have children, either because of the risk that HIV will be passed on to the baby during childbirth or breastfeeding, or out of concern for the child if its parents die prematurely from AIDS. Women who do desire children are thus deemed irresponsible or deviant. This is true also of many women in the North, despite the fact that antiretroviral drugs and caesarean sections are widely available to reduce the risk of maternal mortality or mother-to-child transmission (Welbourn 2006). This sense of risk can also be internalised by positive women themselves, especially when they have not been given comprehensive information about their reproductive options.

Young HIV-positive women experience particular hostility from health workers with regards to having children, encountering dual criticism on account of being young and pregnant, and HIV positive (ICW 2004a). The result is often that women are put under intense pressure from health workers to have an abortion or be sterilised. This is in spite of the fact that abortion is still illegal in many countries and therefore takes place in secret, posing a grave threat to the woman's life, as demonstrated by the fact that 68,000 women still die each year from illegal abortions (World Health Organization 2000). Even if women resist pressure to have an abortion or sterilisation, they are rarely given information on how to reduce the risk of infecting their partner and child – such as information on good practice in infant feeding.

> 'When I went to give birth, a guy there spoke badly. He said that I should be sterilised. Actually, I was fearful and confused…He said there was no reason why I should keep it and I should get an abortion…I couldn't respond then, all I could do was shake my head and feel really bad.'
>
> (Thai woman, Paxton and Welbourn 2004:10)

> 'Some health personnel even threaten the women that if they are not sterilised, they will not receive powdered milk for their babies.'
>
> (ibid)

It is crucial that HIV positive women are supported to make their own reproductive choices about whether and/or when to have children, free from discrimination, coercion and violence. To support HIV positive women in considering their reproductive choices, accurate, impartial and accessible information is required on issues such as: effective contraceptive methods to prevent pregnancy, including recommending dual protection; the effects that HIV will have on a woman's health as the

disease progresses, along with the implications this may have for planning a family; the low risk of transmitting HIV to an uninfected partner while trying to become pregnant; the low risk of mother-to-child transmission in cases where appropriate advice and resources are available; and the possible increase in adverse pregnancy outcomes as a result of being HIV positive (UNFPA/WHO 2006).

3.5 Prevention of mother-to-child transmission (PMTCT)

With ART, safe-delivery and safe infant-feeding, the risk of perinatal transmission of HIV from mother to child is below two percent. Without these interventions the risk increases to between 20 and 45 percent (Guttmacher Institute 2006). These interventions, which comprise part of what are broadly known as Prevention of Mother-To-Child Transmission (PMTCT) programmes, are an effort to reduce the rate of transmission of HIV from a woman to her foetus (unborn baby) or newborn during pregnancy, delivery, or the post-birth period (Center for Reproductive Rights 2005).

The potential benefits of PMTCT programmes are clearly enormous. Unfortunately, inadequate resources mean that in much of the global South, women's only access to ART is a single dose of antiretroviral medication to protect the infant during delivery (UNAIDS/UNFPA/UNIFEM 2004). Without ongoing treatment, many HIV-positive women give birth only to die themselves a few years later (ibid), while others become drug-resistant. Moreover, PMTCT programmes tend to approach women as 'bearers of children' rather than as individuals who themselves require treatment and care. Without an awareness of the particular experiences of women living with HIV/AIDS, and of the rights they have as patients, PMTCT programmes risk violating women's human rights, including their right to provider-patient confidentiality, and their right to access care and treatment for themselves as women and mothers without discrimination (ibid).

It is thus essential that prevention goals do not outweigh the rights of women as patients. Women will be more inclined to participate in programmes if they feel confident that their choices will be respected. Informed consent and confidentiality must be paramount and strict guidelines should be drawn up for PMTCT programmes to enforce this. Health care staff require the skills, knowledge and understanding to treat positive women without being judgemental and to provide them with the information they need to make informed choices (IPPF/ICW 2004). It is also vital that appropriate information and support is provided to assist positive women in deciding whether or not to breastfeed, as well as corresponding advice on how to treat alternative sources of milk, and what to do about complications such as sores in the babies' mouth (ICW 2004f).

4 Legal and economic rights

> ‘Most of the positive women in Nepal are widowed and/or abandoned by their family. This means they have a lot to worry about apart from their sexual and reproductive health. Staying alive and keeping safe are their main concerns.’
>
> (Asha, Nepal, IPPF/ICW 2004: 4-5)

For women and girls living with HIV/AIDS, ensuring the protection of their legal and economic rights – including access to financial resources and property – is as important as protecting their sexual and reproductive health and rights (ICW 2004c). Without resources, women are vulnerable to abuses of power. In contexts where women have few legal or inheritance rights, and where there is a custom of ‘widow inheritance’, widows of men who die of AIDS may be forced to marry their in-laws. Furthermore, where women cannot legally own or inherit land or property, if a woman’s husband dies from AIDS-related illnesses, she will be unable to gain ownership of, or access to, the land. Women who are abandoned by their husband and ostracised from the community because of an HIV positive status are also frequently denied a rightful share of their husbands’ property (Exchange 2006). Without equitable child custody rights, many women also face the possibility of losing access to their children.

This degree of insecurity – the threat of homelessness and destitution – leaves women with few options. Exchanging sex for resources is a survival strategy for many women, who may turn to men for sex in order to buy school clothes or food for their children. In Southern Africa, many adolescent girls enter into sexual relationships with older men in return for school fees, food, and highly sought after consumer goods (UNAIDS/UNFPA/UNIFEM 2004). For other women, sex work may be the only economic option available – providing a more viable livelihood than other alternatives – yet this further compounds the stigma they face (ICW 2004c).

The discrimination and stigma surrounding HIV/AIDS also severely affects the ability of HIV positive women to find and keep work. Women whose HIV positive status is known or suspected within the community may find that people no longer buy their goods. Other women may be sacked by their employers after receiving an HIV positive diagnosis, sometimes after compulsory testing (ibid). Even women who remain employed may suffer intense discrimination in the workplace.

> ‘I felt like I was falling into a huge abyss because I knew what was going to happen at work. And so it was – they sacked me as soon as they found out and most of my so called friends turned their back on me.’
>
> (Mexican woman, ICW 2004c:2)

Among HIV positive drug users in the UK, concerns were raised regarding confidentiality in relation to pension schemes and health questionnaires.

> ‘I was asked to fill in a health questionnaire for pensions and there were specific questions about substance misuse and HIV and Hep [hepatitis] and I was advised not to lie by the union

and I started freaking out because I had just been offered my dream job and if I filled this in truthfully would it be taken away?'

(HIV positive woman drug user, ICW forthcoming)

Women's vulnerability is exacerbated by the largely informal nature of their work, which means that they do not get paid if they are ill or if family members are ill and require care. A UNAIDS report in 2004 showed that 90 percent of care for people living with AIDS takes place in the home (UNAIDS 2004: 118) and is provided overwhelmingly by women and girls, who are frequently unpaid and receive little support or training from the State. Many are also HIV positive and may be in need of care themselves. Girls are taken out of school to provide this care and women are forced to leave work. This leaves them severely impoverished, as household income falls while expenditure increases. Home-based care is often perceived as a 'cost-effective response' to the epidemic, yet in reality it is exploitation of women's unpaid labour, only made possible because care work is seen as 'women's work' and is thus accorded less recognition and value than the work undertaken by men (VSO 2006).

Finding ways to enable girls with HIV to continue their education is essential, such as flexible learning times for those earning a living or helping at home during school hours. Another solution is to provide home-based carers so that girls can continue at school. Financial compensation for the labour of women and girls – through reimbursements, stipends, salaries, or social protection mechanisms such as pensions, child support grants, or cash transfers – would go a long way towards meeting some of the needs of women and girls who are caring for AIDS-patients, while potentially living with HIV/AIDS themselves (ibid). Moreover, when home-based care is paid, men are more inclined to get involved (VSO-RAISA 2005).

Increased educational and employment opportunities, as well as micro-finance and women's property ownership schemes, are crucial strategies for enhancing women's material security. Yet development interventions which aim to improve women's employment and income-generating opportunities risk simply compounding women's heavy work burdens unless efforts are made to encourage men to take greater responsibility for child care and domestic chores (Esplen 2006). Projects that focus solely on women may also reinforce existing stereotypes (women as carers, men as breadwinners, and so on). Involving men, by contrast, can generate a broader consensus on issues which have previously been marginalised as being of interest to women only (ibid).

The business community has an important role to play, by introducing gender-equitable HIV workplace policies and implementing HIV awareness programmes throughout the whole management and staff body (ibid). The involvement of HIV positive women in workplace policy development and implementation to ensure the retention and employment of HIV positive staff, including women, is essential (ICW 2006b). Benefits to staff should include a range of appropriate care and support that is not just focused on the provision of medication – such as complaints procedures for those that experience discrimination. Likewise, all governments should introduce HIV workplace policies and be fully supportive of any parliamentarians who publicly disclosure their HIV status or who express their support for family members with HIV (Paxton and Welbourn 2004).

5 Rights to meaningful involvement

Women and girls living with HIV/AIDS have identified key actions to improve their situations, including demanding recognition of their fundamental human rights; calling for meaningful involvement at all stages of the decision and policy-making process (ICW 2004e); advocating for their sexual and reproductive rights, including the right to decide whether or not to have children; and urging governments to provide accessible, affordable and equitable healthcare (UNAIDS/UNFPA/ UNIFEM 2004). To genuinely address the needs of women and girls living with HIV/AIDS, it is imperative that policymakers and health practitioners prioritise these demands and recognise the expertise of positive women themselves. The 1982 United Nations Declaration of a Programme for Action and the 1994 Paris Principle of Greater Involvement of People Living with HIV/AIDS (GIPA) both uphold the rights to inclusion and strengthening of organisations of people with HIV in all decision-making processes affecting their lives (ICW 2004e). Yet rarely are organisations of HIV positive women involved in decision making (Paxton and Welbourn 2004). Instead, it is often assumed that an HIV positive man can speak on behalf of all HIV-positive people, or that inviting a token HIV-positive woman to give a personal testimony at a meeting constitutes involvement.

> 'We're weary of being asked to attend meetings as an after-thought, to stand up and provide a personal testimony but little else…The issue of 'how I got infected' matters far less than 'what I did next'. We want to be included from the outset in deciding agendas, taking decisions and ensuring their implementation.'
>
> (Roberts 2004, in ICW 2004e:3)

HIV positive drug users are especially marginalised within international policy forums – an alarming omission given the rising rate of HIV infections among injecting drug users, especially in Eastern Europe (ICW, forthcoming). Particular efforts should be made to support HIV positive women facing multiple stigmas – drug users, sex workers, LGBT, migrants, young women, disabled women – and to promoting solidarity between these groups of positive women.

To enable genuine involvement, governments and funders need to invest in the capacity of networks and organisations run by and for positive women to participate meaningfully in the policy-making process, through better funding, as well as by providing training in fund management, strategic planning, and administration, and giving emotional and moral support (ICW 2004e). Only then will the complexity of women's lives – and the contexts in which their reproductive and livelihood choices are grounded – be better understood. Women and girls living with HIV/AIDS have shown great resilience, determination and leadership in households and communities throughout the world. It is vital that we take our lead from their wisdom.

6 Key recommendations

6.1 Supporting women's rights to care, treatment and support

- Ensure that HIV testing is based on the provision of non-judgmental information and support so that women can make informed and voluntary decisions about whether or not to be tested.

- Consult HIV positive women and girls about appropriate locations for service provision, and set up decentralised, mobile health care facilities on the basis of their suggestions.

- Offer HIV-testing and counselling in a range of settings aside from antenatal clinics – workplaces, universities, prisons.

- Train and employ HIV positive women and girls, and positive women's organisations, to promote and distribute ART, and to become pre and post-test counsellors.

- Design holistic treatment programmes which promote good nutrition and support positive women and girls to address the psycho-social issues related to ART side-effects, such as negative body image.

- Link up testing and treatment facilities with existing support groups or encourage new groups to form so that people who test positive can join a group and get support from the start (Bell, E., Mthembu, P., and O'Sullivan, S., paper forthcoming).

- Carry out research into the particular treatment and care barriers faced by socially marginalised groups of women living with HIV/AIDS, including: lesbians, bisexual women and transgender people; sex workers; injecting drug users; female prisoners; women with disabilities; indigenous people; illegal immigrants, refugees and internally displaced people; and women in conflict situations – and support these groups to mobilise.

6.2 Meeting the sexual and reproductive health needs of positive women and girls

- Advocate for the meaningful involvement of positive women at all levels of policy and programming around the areas of HIV/AIDS and sexual and reproductive health and rights;

- Empower women to have control of their sexual and reproductive rights through awareness raising and training;

- Ensure women are aware of their sexual and reproductive rights, and are informed about complaints procedures;

- Support the rights of HIV positive women to decide freely and responsibly whether or not to have children, and to decide the number and spacing their of children, by providing appropriate

education and information – including on safe conception – as well as ensuring access to services;

- Support HIV positive women and girls in choosing a contraceptive method that is suited to their needs, and promote access to male and female condoms, and other forms of contraception, including emergency contraception;

- Ensure that advice on, and access to, safe and confidential abortion services for HIV positive women is freely available;

- Include screening, prevention and treatment for opportunistic infections and HIV-related conditions such as cervical cancer, as part of the treatment package for HIV positive women and girls (ICW 2004b);

- Promote male involvement in sexual and reproductive health programmes;

- Recognise women's rights as patients. Guidelines should be drawn up for PMTCT programmes to ensure that women's rights to informed consent and patient confidentiality are respected;

- Revise the nursing and medical school curricula so that they go beyond health issues, to facilitate understanding of the wider context of positive women's lives – including issues around stigma and discrimination. The need to respect the human rights of HIV positive women should be a core component of the curricula. Health staff who have already qualified should receive this information as part of their job training.

- Provide counselling services for girls and women who have experienced sexual violence;

- Ensure that humanitarian responses to crisis situations include sexual and reproductive health services and counselling (UNAIDS/UNFPA/UNIFEM 2004).

6.3 Protecting women's livelihood opportunities

- Promote micro-finance schemes and women's property ownership schemes to support women's financial independence.

- Assist women's organisations already campaigning for better access to land, property ownership, inheritance rights, and equitable child custody rights (ICW 2004c).

- Support self-help and support groups – as they often help women discover livelihood opportunities and provide space to challenge gender inequality (ibid).

- Support advocacy for the recognition of women's care responsibilities as work; establish a minimum wage for care workers; and establish a body to regulate care work in the context of HIV/AIDS (VSO-RAISA 2005).

- Consider explicitly the impact of home-based care on positive women.

- Provide training and psycho-social support to home-based caregivers.

- Involve HIV positive people in designing and implementing gender-equitable HIV workplace policies and awareness programmes, which promote the retention and employment of HIV positive staff and provide a range of appropriate care and support (ibid).

6.4 Promoting the meaningful involvement of women and girls living with HIV and AIDS

- Recognise the skills and experience of HIV positive women, and positive women's organisations, in responding effectively to the epidemic.

- Invest in the capacity of positive women's organisations to participate fully in the decision-making process.

- Adopt less formal means of consultation to facilitate the participation of women living with HIV.

- Set up training programmes to encourage HIV positive women to participate in the electoral process and other political activities.

- Make particular efforts to support HIV positive women facing multiple stigmas – sex workers, LGBT, drug users, young women – and seek to reduce stigma and promote solidarity between HIV positive women.

Additional references (not already in the bibliography)

Bell, E., Mthembu, P. and O'Sullivan, S. (2007) 'Sexual and Reproductive Health Services and HIV Testing: Perspectives and Experiences of Women and Men Living with HIV and AIDS' *Reproductive Health Matters*, paper forthcoming

Esplen, E. (2006) *Engaging men in gender equality: positive strategies and approaches*, BRIDGE, IDS, http://www.bridge.ids.ac.uk/reports/BB15Masculinities.pdf

ICW (2006b) 'Testing and the Rights of HIV Positive Women', article in *ICW newsletter*, June 2006, http://www.icw.org/node/227

ICW (2004g) 'HIV Positive Women/Girls and Orphans', article in *ICW newsletter*, 2004 http://www.icw.org/tiki-download_file.php?fileId=106

Tallis, V. (2002) *Gender and HIV/AIDS* Cutting Edge Pack, BRIDGE, IDS (English, French, Spanish and Albanian) http://www.bridge.ids.ac.uk/reports_gend_CEP.html#HIV

UNAIDS (2004) *4th Global AIDS Report*
http://www.unaids.org/bangkok2004/GAR2004_html/GAR2004_00_en.htm (English)
http://www.unaids.org/bangkok2004/GAR2004_html_sp/GAR2004_00_sp.htm (Spanish)
http://www.unaids.org/bangkok2004/GAR2004_html_fr/GAR2004_00_fr.htm (French)

UNAIDS/WHO (2006) *AIDS Epidemic Update* (English, French, Spanish, German and Russian)
http://www.unaids.org/en/HIV_data/epi2006/default.asp

Section two: an annotated bibliography

1 Overviews

ICW (2004a) HIV Positive Young Women, *ICW Vision Paper 1*
http://www.icw.org/tiki-download_file.php?fileId=58 (English)
http://www.icw.org/tiki-download_file.php?fileId=48 (French)
http://www.icw.org/tiki-download_file.php?fileId=63 (Spanish)

A group of young HIV positive women from Eastern and Southern Africa met in 2004 to develop a common advocacy agenda. One of their major concerns was that young women living with HIV and AIDS are unable to access their sexual and reproductive rights, such as the right to have children, the right to safe abortion, and the right not to be forced into termination of pregnancy or sterilisation. The fact that young women living with HIV and AIDS are often deterred from accessing services by the judgmental attitudes of health workers was another priority concern. Young women may also lack the time, money and independence to get to clinics, or be concerned that their confidentiality will not be respected. The need for meaningful and active participation of young women living with HIV and AIDS at all levels of decision-making is crucial if these concerns are to be effectively addressed. Several demands are outlined, made by the young women themselves, such as the need for continued access to education for HIV positive girls, for example by providing flexible learning times for those earning a living or helping at home during normal school hours; and better access to information for positive women and girls on safe pregnancy, breastfeeding and abortion.

ICW (2004f) *Visibility, voices and visions: a call for action from HIV positive women to policy-makers*
http://www.icw.org/tiki-download_file.php?fileId=54 (English) (740 KB)
http://www.icw.org/tiki-download_file.php?fileId=56 (French) (780 KB)
http://www.icw.org/tiki-download_file.php?fileId=55 (Spanish) (780 KB)

Drawing on evidence from ICW research, training and workshops, this document highlights the challenges that HIV positive women face on receiving a positive HIV diagnosis. These include fear about the consequences of disclosure; coping with discrimination at work; constraints on access to health services; and having to decide whether or not to have children. For example, HIV positive women are not always in a position to choose how and when to disclose their HIV status. With increasing signs of illness, lack of discretion makes confidentiality almost impossible. To address these issues, practical steps are outlined, directed at policy makers, including:

- Organise intensive public campaigns to promote the active involvement of, and support for, the ongoing work of HIV positive women;
- Promote more open discussion of sexuality and sex acts, including feelings and pleasures, as well as risks and dangers;

- Involve HIV positive women in reviewing and amending discriminatory laws and practices against women, particularly inheritance laws and physical violence;
- Consult HIV positive women and girls with regards to accessible contexts and locations for service provision, and train and employ positive women as service providers.

UNAIDS/UNFPA/UNIFEM (2004) *Women and HIV/AIDS: Confronting the Crisis*
http://www.unfpa.org/hiv/women/docs/women_aids.pdf (PDF) (7,250 KB)
http://www.unfpa.org/hiv/women/report/index.htm (HTML)

Rising rates of HIV infection among women are a major cause for concern. Not only are girls and women highly susceptible to HIV infection – both biologically and as a result of gender inequality and discrimination – they are also less able to access treatment than men. Families of limited means may choose to pay for treatment for men rather than women, and the cost of transportation to clinics may be too high for women who do not earn an income or have limited access to resources. When combined with women's increasing burden of care work, the situation becomes untenable. This report is an urgent call to action to address the triple threat of gender inequality, poverty and HIV/AIDS. It urges governments and policy makers to ensure that national programmes address the constraints that make it difficult for HIV positive girls and women to access and adhere to treatment in the face of opposition and stigma. Health services should provide mobile health clinics, reduce or eliminate fees, provide child care at health centres and offer care to everyone in a family so no one member is treated at the expense of others. Governments and policy makers should also assume responsibility for the health-care needs of people living with HIV/AIDS so that individual women no longer solely bear the burden of their care. The main document is only available in English, but the executive summary is also available in French, Spanish and Arabic.

2 Stigma, discrimination and human rights violations

Paxton, S. and Welbourn, A. (with Kousalya, P., Yuvaraj, A., Pradhan Malla, S and M. Seko) (2004) "Oh! This one is infected!" *C,* Expert meeting on HIV/AIDS and Human Rights in Asia-Pacific, Bangkok, 23-24 March 2004

http://www.icw.org/tiki-download_file.php?fileId=79 (500 KB)

Women under 20 years old are up to ten times more vulnerable to HIV infection than men. They are also significantly more likely to experience AIDS-related discrimination after a positive diagnosis. Women are often blamed for bringing HIV into the family and may be subjected to violence by their spouse or in-laws. A study of AIDS-related discrimination in Asia found that over ten percent of women had lost financial support from family members since being diagnosed as HIV positive, compared with 4.6 percent of men, while 12 percent of HIV positive women had been forced to change their place of residence, compared with 6 percent of men. This paper sets out to explain why a majority of women in the Asia-Pacific region are disproportionately at risk of HIV infection; it documents examples of discriminatory attitudes and actions against HIV positive women in the region; and concludes with recommendations of action by and for all levels of society to counteract these human rights violations. For example, equitable access to barrier methods of contraception (which protect against pregnancy and the transmission of sexually transmitted infections, including HIV) is needed – including the female condom which should be better promoted and subsidized. Mandatory testing of pregnant women must stop immediately and be replaced with voluntary couple counselling and testing; and health staff need support to think about their own HIV status, and assurances that they will not lose their jobs if they are found to be HIV positive.

Center for Advocacy and Research, New Delhi, and Positive Women's Network, Chennai, (2003) *Positive Speaking: Voices of women living with HIV/AIDS*, United Nations Development Fund for Women (UNIFEM)

http://www.unifem.org.in/Positive%20Speaking%20-%20Final%20Book.pdf

In 2002, Positive Women's Network (PWN+) Chennai, in collaboration with UNAIDS and UNIFEM, organised a national consultation on women living with HIV/AIDS. The consultation identified the need to document human rights violations against HIV positive women as an important tool for policy advocacy. This report is a response to this recommendation and is based on a study undertaken in three states in southern India. It documents the experiences of women living with HIV and AIDS and discusses their lack of access to basic services. The individual testimonies reflect four dominant concerns: unacceptable levels of gender discrimination and acute deprivation of girl children; denial of the basic right to live a life of dignity – being subjected to domestic violence and abuse; inadequate access to information, counselling and health care services; and denial of legal rights such as the right to property. To help counter these concerns, information on HIV/AIDS and opportunistic infections must be made available to women through schools and colleges and should be in local dialects to facilitate understanding. Workplace policies that guard against the discrimination of women living with HIV/AIDS, while safeguarding their rights to due processes and entitlements as employees, must also be enforced in the public and private sectors.

ICW (2004d) *HIV Positive Women and Human Rights*, *ICW Vision Paper 4*
http://www.icw.org/tiki-download_file.php?fileId=59 (English)
http://www.icw.org/tiki-download_file.php?fileId=51 (French)
http://www.icw.org/tiki-download_file.php?fileId=64 (Spanish)

Many countries have signed up to international human rights frameworks that oblige them to respect and protect the rights of all people regardless of HIV status and gender. Despite this, HIV positive women are often subject to degrading and discriminatory treatment, causing blame, isolation and shame, and leading to restricted freedom of choice. Gender inequalities can lead to the abuse of women's sexual and reproductive rights, while also undermining their legal, economic and political rights. Women's unequal social, economic, and legal status is increased by a positive HIV status, and vice versa. Violations of reproductive rights faced by HIV positive women include not being allowed the freedom to decide to have children or not to have children, or to decide on the number and spacing of children. In many countries, women are also excluded from inheriting property, evicted from land and homes by in-laws, stripped of possessions, or subject to widow inheritance in order to retain access to their property. Recommendations include: developing accessible legal support and advice services, and promoting the participation of HIV positive women in formulating and implementing rights.

Voluntary Services Overseas-Regional AIDS Initiative of Southern Africa (VSO-RAISA) (2005) ''You Don't Belong Here': Fear, Blame and Shame Around HIV & AIDS', report from the VSO-RAISA Regional Conference, Pretoria, South Africa, October 2005
http://www.vso.org.uk/Images/RAISA_StigmaReportBack_tcm8-7638.pdf (2,800 KB)

In October 2005, delegates from 10 countries gathered in Pretoria, South Africa, for a three-day VSO-RAISA regional conference on tackling the stigma and discrimination experienced by people living with HIV and AIDS. That men and women experience stigma differently was widely documented by the conference participants. This is largely because of the fact that male sexual behaviour is generally condoned while the behaviour of women is judged. Yet one delegate noted that men are sometimes seen as the perpetrators of HIV infections and women as the victims. It was also noted that the media can shape attitudes towards HIV positive women and men. Some media depictions reduce all people living with HIV/AIDS to an image of a poor black woman. In other cases, men living with HIV/AIDS are portrayed as celebrities while women are seen as victims; and there is sometimes an overemphasis on young girls to the exclusion of boys and men, while gay and lesbian youth are ignored. This report of the conference contains summaries of the presentations made, including those on gender discrimination, and highlights the issues arising from the discussions.

The Global Network of People Living with HIV/AIDS (GNP+) and ICW (2005) ***Position Statement: Injecting Drug Users and Access to HIV Treatment***
http://www.gnpplus.net/cms-downloads/files/IDUEN.pdf (English)
http://www.gnpplus.net/cms-downloads/files/IDURU.pdf (Russian)
http://www.gnpplus.net/cms-downloads/files/IDUES.pdf (Spanish)

In 2005, there were an estimated 13.2 million injecting drug users worldwide, 80% of whom live in developing and transitional countries. A universal characteristic of injecting drug use-related HIV epidemics is that although males constitute the majority of those infected in the early stages, sexual transmission to male and female partners as well as to new-born children through mother-to-child transmission may contribute to HIV transmission to the general population. There are specific issues related to injecting drug use and women, including an increased risk of HIV infection through involvement in sex work to provide money for drugs. HIV positive women who are also injecting drug users are often in the 'frontline' when it comes to facing stigma and discrimination, particularly in relation to whether they are 'suitable' mothers. This GNP+/ICW position statement on harm reduction outlines global commitments relevant to injecting drug-users and identifies essential programmatic actions needed to prevent transmission of HIV through injecting drug use, such as harm reduction programmes, needle and syringe exchange programmes, and access to antiretroviral therapy.

ICW (2006) HIV positive women and drug and alcohol use, ***Vision paper 6***
http://health.osf.lt/downloads/news/HIV%20positive%20women%20and%20drug%20use%20SP.doc

Silent Voices, a participatory ICW project carried out by and for HIV positive women, researched services available for HIV positive drug/alcohol using women living in London, UK, and explored their experiences of using these services. The women reported that present-day services do not support their specific needs, and many expressed feelings of being invisible and discriminated against, even within the HIV community. The women also articulated their concerns about disclosing their HIV status and drug use to existing or new partners, family and friends, their children, colleagues and employers. Would existing partners leave them? Would their children accept their diagnosis? Discussions and training regarding disclosure should be offered to women living with HIV. These can be facilitated by other HIV-positive women who can share their experiences of what worked and what did not. Specific peer support groups for HIV positive women who are drug users should also be encouraged as a way of supporting each other and exchanging information and experiences.

Act Up Paris (2006) Women sex workers and HIV (French)
http://www.actupparis.org/article2083.html

Act up-Paris is an activist and a lobby group based in Paris. For them fighting AIDS also means fighting all kinds of discrimination, putting pressure on government and raising public awareness at the same time. This online publication includes an article on access to care and prevention for female HIV-positive sex-workers. It points out that health providers must be aware of sex-workers' work

routine and time schedules in order to offer good care and treatment to the patients, and they should not assume that sex-workers will stop working when diagnosed HIV-positive. Another article in the publication discusses the ethics of medical trials on sex-workers. It explains that a new drug was tested in Cambodia on a group of sex-workers. The communication between researchers and sex-workers was very poor and researchers were often lying deliberately to the participants to hide potential side effects of the drug. The need for an honest flow of information between participants and researchers is essential both for the success of medical trials and for the protection of the participants. Original title in French: Travailleuses du sexe et VIH.

3 Access to care, treatment and support

ICW (2004b) *Access to care, treatment and support*, ICW vision paper 2
http://www.icw.org/tiki-download_file.php?fileId=60 (English)
http://www.icw.org/tiki-download_file.php?fileId=49 (French)
http://www.icw.org/tiki-download_file.php?fileId=65 (Spanish)

Antiretroviral treatment (ART) has turned HIV into a more manageable chronic condition which may no longer be a death sentence. However, treatment is not just about providing ART; care and support are also vitally important. This paper, one of five vision papers produced by ICW, identifies barriers to women's access to treatment. The cost of ART is a major obstacle. Yet even when treatment is free there are other costs involved – the cost of transport to the clinic, the time lost from work and caring duties. These barriers are often more severe for women than men as women have to account for their time to their husbands or family members. Women living with HIV/AIDS may also face discrimination because of social values surrounding the importance of female purity, and this affects access to a range of information, treatments and support. Training and employment of HIV positive women as treatment promoters and ART distributors is an important step towards ensuring equitable access to treatment. Other recommendations include: support holistic health approaches which promote good nutrition and deal with psycho-social issues, and support programmes which recognise women's roles as care givers and the immense traumatic impact of so many deaths on everyone's lives.

ICW (2006) *Mapping of Experiences of Access to Care, Treatment and Support*
http://www.icw.org/files/Namibia%20ACTS%20mapping.doc (Namibia)
http://www.icw.org/files/Tanzania%20ACTS%20mapping.doc (Tanzania)
http://www.icw.org/files/Kenya%20ACTS%20mapping.doc (Kenya)

As a positive woman, how do you try to stay healthy? What barriers do you face in trying to access medication? In 2006, ICW mapped positive women's experiences of access to care, treatment and support in three countries – Tanzania, Kenya and Namibia. Treatment is meant to be free in all three countries, yet focus group discussions with HIV positive women and health care workers revealed a number of factors that negate women's ability to access and use antiretrovirals (ARVs) to improve their health. Partner control can make it impossible for women to access health services. Partners may refuse to let women go to the hospital or deny them the money for treatment. In other cases women faced pressure from partners to share their medications with them. Having to bribe health care workers to ensure access to care, treatment and support was reported by all focus groups. Other problems included the financial and time costs of travelling to clinics or health centres; lack of confidentiality; unavailability of treatment; and poor nutrition leading to ill-health, problems with adherence, and pressure to sell medications. Changes needed to improve treatment, care and support include better transport services, health services near villages, income generation opportunities, and improved nutrition.

The Global Coalition on Women and AIDS (GCWA) and ICW (2006c) - *Access to Care, Treatment and Support,* ICW Fact Sheets
http://www.icw.org/files/ACTS-ICW%20fact%20sheet-06.doc

Gender inequalities can constrain HIV positive women's access to care, treatment and support as well as their ability to use treatment, information and advice to improve the quality of their lives. This short fact-sheet identifies a range of barriers faced by HIV positive women in accessing care, treatment and support. For example, even when antiretroviral therapy (ART) is free, women have found that costs associated with travel, good nutrition, childcare, and treatment for related health problems puts the chance of leading a healthy life with HIV out of their reach. Lack of decision-making power is another major obstacle, as women often have to ask relatives for permission to access services. The demands of looking after a family often preclude women's own health care needs and some women report selling medication on the black market to pay for much needed food. A further issue is the lack of women-specific and age-specific clinical research and health centre data available, leading to confusion concerning treatment options for women. Recommendations emphasise the importance of:

- Carrying out more research into opportunistic infections specific to women and HIV-related conditions such as cervical cancer.
- Training and employing HIV positive women as treatment promoters and ART distributors.
- Promoting mobile and decentralised treatment distribution.
- Supporting holistic health approaches which promote good nutrition and deal with psycho-social issues.

Aphane, D. and ICW (2006) *Advocacy tool – access to care, treatment and support for women living with HIV and AIDS in Swaziland*, ICW
http://www.icw.org/files/ACTS%20-%20SZ%20-%20final%2005-06.doc (440 KB)

Experience shows that the active involvement of HIV positive women at all levels of decision-making, including policy formulation, is essential to overcoming gendered barriers to accessing HIV/AIDS treatment, care and support. Accordingly, POLICY collaborated with ICW to pilot test a set of approaches for identifying and addressing gendered barriers to treatment in Swaziland. The project focused primarily on building the advocacy capacity of HIV positive women by training them in the skills required to engage in policy dialogue and shape policy planning and implementation processes. Key advocacy issues are identified, including: financial and in kind support for women engaged in community and home-based care activities, decentralisation of treatment services to improve accessibility in remote areas; equitable property ownership and inheritance laws; and legislation recognising violence as a factor limiting women's ability to make decisions especially related to HIV and AIDS, and to access appropriate treatment, care and support for HIV and AIDS. For each issue identified, possible advocacy openings are outlined, including information on stakeholders who are already working on these issues.

Reyes, H. (2000) *Women in Prison and HIV*, International Committee of the Red Cross
http://www.icrc.org/web/eng/siteeng0.nsf/html/59NAR6

Women prisoners often come from marginalised, socially deprived and often high-risk backgrounds for HIV. Many of them may already be infected with HIV on entering prison. This paper argues that prison medical care should be tailored to the special needs of women in prison, and be equipped and staffed to recognise and manage the diseases that facilitate HIV transmission or accompany AIDS. Particular care should be given to concurrent diseases, such as sexually transmitted infections, and accompanying diseases like tuberculosis. Most importantly, prison authorities should take advantage of women's stay in custody to provide education on prevention and on how to stay healthy. Prison may be a unique moment in these women's lives in which they have access to such care and counselling.

4 Sexual and reproductive health and rights

Guttmacher Institute (2006) ***Meeting the Sexual and Reproductive Health Needs of People Living with HIV***
http://www.guttmacher.org/pubs/IB_HIV.pdf

As the prospects for people living with HIV have improved worldwide, AIDS activists and the global public health community have increased their focus on quality-of-life issues as well as length-of-life issues. Regardless of HIV status, the ability to express one's sexuality and the desire to experience parenthood are, for many, central to what it means to be human. Yet people living with HIV/AIDS – especially women – are often seen as irresponsible if they desire to have children, or face criticism for being sexually active. This paper argues that concerted actions on several fronts are needed: to ensure that women with HIV are not coerced or pressured into terminating a pregnancy, or into using certain contraceptive methods such as sterilisation; to expand contraceptive services; to offer psychosocial support for women contemplating childbearing; and to provide nondirective, nonjudgmental and confidential counselling to HIV-positive women, including those faced with unplanned pregnancies. Associations and networks of HIV positive people and community-based organisations run by and for people with HIV have a key role to play in realising these goals.

IPPF/ICW (2004) ***Dreams and Desires: Sexual and Reproductive Health Experiences of HIV Positive Women*****, IPPF**
http://content.ippf.org/output/ORG/files/5332.pdf (3,950 KB)

HIV positive women want sex, love and children just as much as anyone else. This is one clear message from these personal accounts by 13 positive women from Bolivia, Nepal, Kenya, Ukraine, Nigeria, Thailand, Swaziland, England, Honduras, South Africa, Belarus, Iran, and Sudan. Their stories bring in a human dimension to the epidemic, as well as providing guidance for policy in the area of the sexual and reproductive health and rights of people living with HIV/AIDS. Many of the women express the need for prevention services and accurate information. They also highlight the need for support in addressing the many psycho-social issues related to anti-retroviral (ARV) side effects and complications, as well as the freedom to make choices about whether and/or when to have children. Access to condoms, both male and female, is seen as critically important as a protective method against re-infection and unwanted pregnancies. Other issues raised include the need for: regular and reliable access to ARVs, adequate training of health care workers who work with HIV positive women, improved reproductive health services, and the need to include HIV positive women in the development of HIV and AIDS prevention, care and treatment programmes.

Bell, E. and Van Beelen, N. (2006) *Exchange on HIV/AIDS, Sexuality and Gender*, Royal Tropical Institute (Autumn 2006 edition)
http://www.kit.nl/smartsite.shtml?ch=FAB&id=8468 (500 KB)

This issue of the quarterly magazine Exchange focuses on the pressing concerns faced by women living with HIV and AIDS globally. It criticises sexual and reproductive health programmes and policies for failing to recognise the complexity of women's lives and the contexts in which their sexual and reproductive choices are situated. For example, gender inequalities mean that women's sexual relations are often enacted from a position of lower status vis-à-vis a male partner. This affects their ability to negotiate safer sex. It also prohibits them from accessing treatment and other health services and from acting on advice given to them by service providers. Other topics addressed in this issue include: the ABC (Abstinence, Be faithful, use a Condom) approach to HIV/AIDS prevention; the loss of property and land by women living with or affected by HIV/AIDS in India; the use of 'memory work' – a community-led approach designed to improve communication between guardians and parents living with HIV and their children; and the lessons learned by the non-governmental organisation PROFAMILIA in its efforts to introduce HIV/AIDS treatment into sexual and reproductive health clinics in the Dominican Republic.

Engenderhealth/UNFPA (2006) *Sexual and Reproductive Health Needs of Women and Adolescent Girls Living with HIV: Research Report on Qualitative Findings from Brazil, Ethiopia and the Ukraine*
http://www.unfpa.org/upload/lib_pub_file/619_filename_srh-of-hiv-positive-women.pdf (PDF)
http://www.unfpa.org/upload/lib_pub_file/620_filename_srh-of-hiv-positive-women.doc (Word)

Despite the growing magnitude of the HIV/AIDS pandemic, health interventions that focus on providing care and treatment for HIV positive women have come at a slow pace. Most women do not know their HIV status until they become pregnant and are tested as a part of antenatal care. Due to antenatal care, more women than ever are accessing voluntary HIV counselling and testing (VCT) and prevention of mother-to-child transmission (PMTCT) programmes in many developing countries, however the breadth and quality of services provided is still inadequate. In 2005, research teams in Brazil, Ethiopia and the Ukraine carried out focus group discussions and in-depth interviews with women and adolescent girls living with HIV, and with the male partners of women living with HIV, health care providers, and policy makers. The research explored the sexual and reproductive health needs of HIV positive individuals and probed issues relating to family planning, sexually transmitted infections, breast and cervical cancer, maternity care services and the prevention of mother-to-child transmission. The findings suggest several areas for further research, including: exploring approaches to making PMTCT services more widely available by integrating PMTCT into health services in rural areas; and conducting research into hormonal contraceptive use by HIV positive women to provide alternatives to condoms.

De Bruyn, M. (2002) Reproductive choice and women living with HIV/AIDS, Ipas
http://www.ipas.org/publications/en/repro_choice_hiv_aids.pdf

Prevention of mother-to-child transmission (PMTCT) has become a major element of HIV/AIDS programmes. One unfortunate consequence of this is that women living with HIV/AIDS have been approached as 'vectors of HIV transmission'. Often they experience pressure from health care providers not to become pregnant. Those who do become pregnant may be coerced into having abortions, or may feel pressure to use PMTCT measures such as caesarean sections or the avoidance of breastfeeding. Yet in communities where breastfeeding is the norm, women may fear that if they avoid breastfeeding others will assume that they are HIV positive. In addition, many women living with HIV/AIDS do not have access to breast milk substitutes. This report, based on interviews with informants in Australia, India, Kenya, South Africa and Thailand, discusses the barriers faced by women living with HIV/AIDS in exercising their sexual and reproductive rights. Recommendations include:

- Carry out education programmes at the grass-roots level to educate women regarding their anatomy, biology and reproductive functioning.
- Increase education on contraception for women living with HIV/AIDS, including the issue of unprotected sex between couples of different HIV status.
- Integrate comprehensive counselling on HIV/AIDS and pregnancy into nursing and medical school curricula.

Feldman, R., Manchester, J. and Maposhere, C. (2002) ***Positive women: voices and choices: A project led by positive women to explore the impact of HIV on their sexual behaviour, well-being and reproductive rights, and to promote improvements in policy and practice.***
http://www.icw.org/icw/files/VoicesChoices.pdf (630 KB)

What is the impact of living with HIV for women in Zimbabwe? The Positive Women: Voices and Choices project was initiated by ICW to provide information about HIV positive women's reproductive health and rights in a way that would allow the voices of HIV positive women to be heard, open up choices available to HIV positive women, and identify appropriate areas for advocacy. This report, which presents findings from Zimbabwe, highlights the overriding stigma and discrimination attached to carrying the virus. Women living with HIV/AIDS find it difficult to discuss sexual and reproductive health needs with health care workers, including the desire to have children. In addition, they tend not to be fully informed about how to reduce transmission of HIV to their children. Being HIV positive also reduces household income, exacerbating women's poverty. Their only means of attaining economic security may be through having sexual relations with men, which can intensify the stigma they face. This report recommends intensive public campaigns to remove stigma and discrimination, and emphasises the importance of strategies to increase women's financial independence – such as micro-credit schemes and financial support for carers unable to work. The need for comprehensive HIV-related training for traditional healers and the inclusion of traditional healers in HIV programmes is also highlighted.

Merkel, J. (2006) *Advocacy tool: the sexual and reproductive rights and health of HIV positive women in South Africa*, ICW
http://www.icw.org/files/SRHRs%20South%20Africa%20-%2006.doc

South Africa is said to be the country with the highest total number of people living with HIV and AIDS. In 2004, it was estimated that 50.75% of those infected between the ages of 15-49 years were women, yet advocacy work had revealed that HIV positive women in South Africa were experiencing considerable barriers in accessing services at the family, community and national levels. In response, the International Community of Women living with HIV and AIDS began a process to identify policy and programmatic gaps relating to the sexual and reproductive health rights of women living with HIV/AIDS in South Africa. This document consolidates the information gathered, identifies advocacy strategies, and presents lessons learned. One key advocacy goal is to lobby at the national and provincial level for good quality sexual and reproductive health service delivery in which positive attitudes of providers and confidentiality are integral to performance appraisal. Another goal is to advocate for comprehensive woman friendly service delivery that encompasses a broad range of services, including: all barrier methods; sexual and reproductive health and rights education and information; support to survivors of intimate violence; cervical cancer screening; voluntary counselling and testing; and prevention of mother to child transmission.

Center for Reproductive Rights (2005) Pregnant *Women Living with HIV/AIDS: Protecting Human Rights in Programs to Prevent Mother-to-Child Transmission of HIV*
http://www.reproductiverights.org/pdf/pub_bp_HIV.pdf

Prevention of Mother-to-Child Transmission (PMTCT) programmes are designed to reduce the rate of transmission from a woman to her fetus (unborn baby) or newborn during pregnancy, delivery, or the post-birth period. While the benefits of PMTCT programmes are considerable, they are primarily conceived of as prevention programmes for infants, leaving the concerns of women living with HIV/AIDS largely invisible and ignoring their rights as patients. This briefing paper addresses the fundamental human rights standards that governments must uphold in creating PMTCT programmes. These standards include the right to informed consent, provider-patient confidentiality, and health-care access without discrimination. To ensure that women are treated with dignity and respect through every phase of HIV/AIDS prevention, treatment, and care, recommendations for policymakers are outlined:

- Remember that the woman is the patient. Respect for women's dignity and rights encourages informed decision-making among women, who may be more willing to participate in programmes once they know their decisions will be respected.
- Increase health providers' understanding of the links between human rights and HIV/AIDS programming through training.
- Reduce stigma by integrating PMTCT programmes within prenatal care facilities rather than making women go to specifically designed facilities to access PMTCT services which may reveal their HIV status to the community.

EngenderHealth/Harvard University/ICW/Ipas/UNFPA (2006) *Sexual and Reproductive Health of HIV Positive Women and Adolescent Girls: A Dialogue on Rights, Policies and Services,* Global Electronic Forum, Report on Results
http://www.unfpa.org/upload/lib_pub_file/621_filename_e-forum_srh-hiv-positive-women.pdf

How have international human rights documents or advocacy efforts facilitated HIV positive women's access to prevention, treatment and care services, if at all? How can we advocate for stronger enforcement of positive women's human rights? These are some of the questions that were debated during two parallel electronic discussions in 2005, one of which was open to all professionals and women with HIV/AIDS, the other of which was open only to HIV positive women. 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 discussions. Another major theme was the lack of basic services responsive to the needs of HIV positive women. Among those mentioned included the inaccessibility of health centres and the lack of respect for female patients' rights by health care workers. The need for training of health training providers on stigma, discrimination and client's rights was highlighted, both for providers already working with HIV positive clients, and for students of medicine and nursing, so that by the time they enter the workplace they are capable of dealing with HIV positive patients with the respect and dignity they deserve.

The Global Coalition on Women and AIDS (GCWA) and ICW Fact Sheets (2006b) - Sexual and Reproductive Health Rights
http://www.icw.org/files/SRHR-ICW%20fact%20sheet-06.doc

This short fact-sheet frames key issues and advocacy messages based on the findings of project work by ICW on the sexual and reproductive rights of HIV positive women. It defines sexual and reproductive health and rights (SRHR); outlines the instruments that enshrine SRHR and wider rights to equality, health, life and dignity, and lists some of the main sexual and reproductive health concerns cited by HIV positive women, such as:

- Lack of commitment to accelerated research on microbicides and other women-controlled barrier contraceptive methods;
- Violation of women's legal and economic rights, leaving them unable to protect their SRHR – such as widow inheritance, lack of access to property inheritance and unequal employment opportunities;
- Community disapproval for continuing to have sexual relationships;
- Lack of access to regular sexual health screening, including pap smears to detect cervical cancer; and
- Pressure to abort, be sterilised or take contraceptives in order to access treatment or other services, or the withholding of such services entirely.

Recommendations made include: advocate for the meaningful participation of women living with HIV at all levels of policy and programme formulation; incorporate enforceable human rights and gender

indicators into national responses to HIV and AIDS; and advocate for access to equal employment opportunities and productive assets.

Welbourn, A. (2006) 'Sex, Life and the Female Condom: Some Views of HIV Positive Women', *Reproductive Health Matters* 14.28:32-40
http://www.aidsportal.org/Article_Details.aspx?ID=3372

This paper offers insights into the experiences of HIV positive women with the female condom, drawing on the responses of 18 ICW members to an email survey conducted in 2005. Major reported barriers to female condom use included cost and sporadic or limited access. All respondents talked about needing to negotiate the use of female condoms with their male sex partners. Most felt more in control during sex when using the female condom than with the male condom or unprotected sex. Concerns about female condoms were common among women who have never used one, but those who had used the female condom for long periods of time said good things about it. Women reclaiming their bodies is a central part of the joy and the challenge of promoting the female condom. Female condoms could make a critically important contribution to protecting HIV positive women's sexuality and continued sexual activity, as a fundamental part of their sexual and reproductive rights, if only they were more widely available and affordable.

Peixoto Caldas, J. M. (2003) *HIV, AIDS and women who have sex with women (El VIH, el SIDA y las mujeres que tienen relaciones sexuales con mujeres (WSW)*)
http://www.aidscongress.net/article.php?id_comunicacao=175 (Spanish)

Although sex between women is considered lower risk than heterosexual sex, it can still transmit HIV. Women who have sex with women (WSW) can reduce the risk of contracting HIV by being aware of their own HIV status and revealing it to their partner. This can help encourage negative women to modify their sexual behaviour to reduce their risk of infection, and positive women to modify behaviour to reduce risk of transmission. Other recommendations include to use condoms during any genital contact with men, or when sharing sex toys, and to use a latex barrier when having oral sex with women or men. It is vital that health professionals remember that the sexual identity of a person does not necessarily predict their behaviour (for example some lesbian women may also sleep with men), and that any preventive measure targeting WSW must take into account possible risky behaviour, such as the use of injectable drugs and unprotected sex with men.

Fundacion para estudio e investigacion de la mujer, (2004) ***Reproductive decisions and pregnancy by women living with HIV/AIDS: Recommendations for health providers.***
(*Decisiones Reproductivas y Embarazo en las Mujeres que Viven con VIH/SIDA: Recomendaciones para el Equipo de Salud*.)
http://www.feim.org.ar/Deciones_Reproductivas_Recomendaciones.pdf (Spanish)

Often HIV positive women do not have access to information on their reproductive rights, whether or not they want to have children. It is vital that health services do not discriminate, and support them in making informed choices. This 4-pager aims to help health staff to provide HIV positive women with such information. If a woman living with HIV decides to have children she must be advised on what to do to prevent HIV transmission to the baby, and on any interactions between retroviral medication and pregnancy. Tips on assistance, support and advice around assisted insemination and prenatal care are provided as well as around giving birth and breastfeeding. Advice around types of contraception and safe termination are also given.

5 Violence against HIV positive women

The Global Coalition on Women and AIDS (GCWA) and ICW (2006a) Violence against HIV positive women, *ICW fact sheet*

http://www.icw.org/files/VAW-ICW%20fact%20sheet-06.doc

How do HIV/AIDS and other public services, policies and programmes address issues of violence against women (VAW)? How do services that deal with violence address the issues of women who are HIV positive? This fact sheet considers the connections between violence and gender inequalities for women living with HIV and AIDS. Women are often the first member of a household to discover their HIV status through anti-natal testing. This can result in blame, violence and rejection from partners, in-laws and the wider community. Internalised stigma can also undermine a woman's confidence to leave or confront an abusive situation. Fear of disclosure – as a result of violence – can also be a barrier to accessing treatment, especially where women have to travel long distances to reach health services, hospitals or clinics, and may need a husband's permission to make or pay for the journey. The result can be that women seek help at the last minute when they are really sick. Responding to these concerns requires an awareness of VAW and its relationship to HIV as rooted in unequal gender relations – rather than solely within a public health framework.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) (2004) *Violence against Women and AIDS*

This fact sheet analyses the issue of violence against women and its relationship to AIDS. It argues that besides being a major human rights and public health problem worldwide, violence against women increases female vulnerability to HIV. Fear of violence prevents women from accessing HIV/AIDS information, being tested, disclosing their HIV status, accessing services for the prevention of HIV transmission to infants, and receiving treatment and counselling, even when they know they have been infected. This is particularly true where HIV-related stigma remains high. The high incidence of non-consensual sex, women's inability to negotiate safer sex, and in many cases fear of abandonment or eviction from homes and communities, present extreme challenges - particularly for women who lack economic means. Married women are at risk as there is particular resistance to using condoms within marriage. Women face additional obstacles due to the pervasiveness of discriminatory legal frameworks which fail to guarantee equal rights or equal protection before the law. Leadership at global, national and community levels must be mobilised to promote the education and legal status of women and make violence against women unacceptable. For a copy of this publication, please contact: UNAIDS Information Centre, V-building, Office 102, 20 avenue Appia, 1211 Geneva 27, Switzerland , Telephone: +41 22 791 3666, Email: unaids@unaids.org

Welbourn, A. (2006) 'Man Hunt Intimacy: Man Clean Bathroom': Women, Sexual Pleasure, Gender Violence and HIV, *IDS Bulletin 37*:5
http://www.ntd.co.uk/idsbookshop/details.asp?id=952

Men's contribution – or lack of it – to household tasks and expenditure and the daily burden of running a home is closely linked to sexual dissatisfaction, gender-based violence and HIV/AIDS. Men seek comfort by having sex with other women, and their wives also turn to other men for sex in order to buy school clothes for their children or food for the daily meal. Yet it is possible to break out of this cycle of economic dependency and physical, sexual and psychological violence. Girls' education and the prospect of an independent income is the key factor which can break the cycle of women's dependency. Promoting mutual understanding around sex is also important. For example, community-based programmes have played a part in breaking this negative cycle, especially among women who are past school age, by helping people to become less judgemental and more understanding of others' life experiences. In the Gambia, for instance, men have learnt the importance of the female orgasm and now recognise that the 'wham, bang thank you ma'am' approach to sex leaves women emotionally and sexually unsatisfied. For HIV positive women, such workshops can also provide the skills to reclaim their bodies from the clutches of an HIV diagnosis; to learn about what gives them pleasure; and to develop a more loving, mutually respectful and satisfying relationship with those with whom they choose to have sex. You can order this IDS Bulletin through the IDS Bookshop.
Tel: +44 (0)1273 678269; fax: +44 (0)1273 621202
email: bookshop@ids.ac.uk
web: http://www.ntd.co.uk/idsbookshop/details.asp?id=952

6 Livelihoods options

ICW (2004c) *HIV Positive Women, Poverty and Gender Inequality*, *ICW vision paper 3*
http://www.icw.org/tiki-download_file.php?fileId=62 (English)
http://www.icw.org/tiki-download_file.php?fileId=50 (French)
http://www.icw.org/tiki-download_file.php?fileId=67 (Spanish)

Gender inequality and poverty not only increase the risk of HIV but also leave women more vulnerable than men to its impact. An HIV positive diagnosis compounds the problems women face in finding and keeping work. Many women, including HIV positive women, work in the informal sector. This may provide flexible opportunities for women to earn a living, but when informal sector workers or family members are ill they do not get paid for the work they miss. Moreover, stigma and gender inequality combine to make it difficult for HIV positive women to obtain resources and customers for small businesses. Those who sell goods may find that people avoid their stall; women farmers may lose access to land; and employers sometimes fire people after an HIV positive diagnosis. Strategies to increase women's financial independence, such as micro-credit schemes, are thus essential to expand women's livelihood opportunities. Financial support for carers who may be unable to work is also vital. HIV positive people should be involved in workplace policy development and implementation, to ensure that policies promote the retention and employment of HIV positive staff and ensure that benefits include appropriate care and support.

UK Consortium on AIDS and International Development (2003) *Working Positively – A guide for NGOs Managing HIV/AIDS in the workplace*
http://www.aidsconsortium.org.uk/Workplace%20Policy/Good%20Practice%20PDFs%20&%20other%20docs/Good%20practice%20guide.pdf

HIV and AIDS are most prevalent in adults in their productive prime. As a result, addressing HIV/AIDS in the workplace is becoming a priority for governments, commercial organisations and non-governmental organisations (NGOs). However, gender differentials need to be taken into account when developing HIV/AIDS workplace strategies. This applies not only to education and prevention programmes which should incorporate a clear gender focus, but also in treatment and care – for example providing access to treatment to prevent mother-to-child transmission. This guide, aimed at international NGOs, is designed to illustrate the approaches being taken by NGOs to HIV/AIDS workplace strategies, and to develop a provisional guide to good practice for NGOs. Key messages to come out of the review include the fact that People Living with HIV/AIDS can add enormous value to education and awareness raising programmes by bringing home to staff the reality that HIV infection can happen to anyone. Successful workplace strategies also need to ensure both commitment from the top to motivate action, and buy-in from all levels of staff.

International Labour Organisation (ILO) (2002) *Implementing the ILO Code of Practice on HIV/AIDS and the world of work: an education and training manual*, Geneva: International Labour Office

http://www.oit.org/public/english/protection/trav/aids/code/manualen/complete.pdf (English) (1,500 KB)
http://www.oit.org/public/english/protection/trav/aids/code/manualfr/implementingthecodef.pdf (French) (1,650 KB)
http://www.oit.org/public/english/protection/trav/aids/code/manulaes/manuales.pdf (Spanish) (2,250 KB)

How do gender roles and relations affect the world of work, and what action can be taken in the workplace to promote equality and empower women in the fight against HIV/AIDS? Women's lower status in society and constraints on their access to income and resources make them more vulnerable to the economic impact of HIV/AIDS. Women are more likely to be in the urban informal sector, in subsistence farming, or in the most poorly paid jobs in the formal sector. This means a low income for most and little social or economic security, in terms of savings, insurance or social security. Women also often find themselves in positions of weakness and dependence within the workplace which easily lead to sexual harassment and abuse. Any action that strengthens the position of women will help the fight against HIV/AIDS - firstly, by challenging attitudes and structures that disadvantage women and, secondly, by providing a greater range of economic alternatives. This module forms part of a manual designed to help the International Labour Organization's (ILO) partners apply the ILO Code of Practice on HIV/AIDS and the world of work, which was adopted in May 2001. This module focuses on the gender dimensions of HIV/AIDS and the world of work, and provides learning activities to address these issues – including tackling embarrassment in talking about sex, encouraging condom use, and thinking about the needs of women workers. Also available in Spanish and French:
Recomendaciones prácticas de la OIT sobre el VIH/SIDA y el mundo del trabajo (Spanish)
http://www.oit.org/public/english/protection/trav/aids/code/manulaes/manuales.pdf
Mise en œuvre des directives pratiques du BIT sur le VIH/SIDA et le monde du travail (French)
http://www.oit.org/public/english/protection/trav/aids/code/manualfr/implementingthecodef.pdf

Voluntary Services Overseas (VSO) (2006) *Reducing the Burden of HIV and AIDS Care on Women and Girls*

http://www.vso.org.uk/Images/RBHACWG_tcm8-8415.pdf

This policy briefing highlights the crisis in delivering equitable health care for people living with HIV and AIDS, and the overwhelming burden it places on women and girls. HIV and AIDS has brought an increased need for community and home-based care. Due to traditional gender norms and unequal gender relations it is the women and girls in the communities who are the primary caregivers, whilst possibly being HIV positive, and often needing care themselves. Many women and girls have left work (both formal and informal) and school to provide this care, and most have taken on this role in addition to their existing reproductive and productive roles. As well as lost opportunities, many caregivers experience severe physical and psychosocial effects including stress, burnout and exhaustion, which affect the individual and their family's well-being. For women and girls who are themselves living with

HIV and AIDS, this places an enormous strain on their health. VSO are calling for financial support and/or compensation for women's labour, through reimbursements, stipends, salaries or improved social protection mechanisms such as: pensions, child support grants, or cash transfers, which particularly target women, and older and child caregivers. It is also crucial to increase women's access to land, inheritance rights, credit and income generating activities.

Peacock, D. (2003) 'Men as Partners: Promoting Men's Involvement in Care and Support Activities for People Living with HIV/AIDS', paper prepared for the United Nations Expert Group Meeting on 'The role of men and boys in achieving gender equality', Brazil, 21 to 24 October 2003

http://www.un.org/womenwatch/daw/egm/men-boys2003/EP5-Peacock.pdf

In South Africa, as in many parts of the world, men often act in ways that leave women and girls disproportionately shouldering the burden of providing care and support to people living with HIV/AIDS. Despite this, little has been done to date to develop interventions that explicitly encourage men to play a more active role in caring for their partners and children. This paper, which was written for the UN Expert Group Meeting on "The role of men and boys in achieving gender equality", argues that an important step in alleviating the burden of care and support borne by women is to challenge rigid ideas about masculinity which disassociate men from caring roles. It is also important to create opportunities for men to learn the skills necessary to provide care to people living with AIDS. For example, at a recent Men and Partners (MAP) workshop in Johannesburg, the male participants were encouraged to take part in a cooking competition. Most importantly, effective interventions need to present men as potential partners capable of playing a positive role in the health and well being of their partners, families and communities.

International Planned Parenthood Federation (IPPF) and The Global Network of People Living with HIV/AIDS (GNP+) (2005) *Fulfilling Fatherhood: Experiences from HIV Positive Fathers*

http://www.ippf.org/downloads/HIV/FulfillingFatherhood.pdf

HIV positive fathers often play a pivotal – and positive – role in shaping the lives of their children and families. This is one clear message from these personal accounts by thirteen HIV positive fathers from across the globe. Yet these stories also attest to the complexities of fathering within the context of HIV/AIDS, particularly the difficulty of disclosing an HIV positive status to your own children. Men living with HIV also have specific sexual health concerns which are frequently neglected, and they often lack information on how to have a healthy sex life. Acknowledging and responding to the sexual and reproductive health issues and desires of HIV positive men and fathers is vital. For example, counselling and testing for sexually transmitted infections needs to become more 'man-friendly'. Fathers also need therapy groups and a place to share challenges and support as positive fathers. Most importantly, more needs to be done to promote a positive image of positive fathers.

7 Participation, leadership and voice

ICW (2004e) Participation and Policy Making: Our Rights, *ICW vision paper 5*
http://www.icw.org/tiki-download_file.php?fileId=61 (English)
http://www.icw.org/tiki-download_file.php?fileId=52 (French)
http://www.icw.org/tiki-download_file.php?fileId=66 (Spanish)

The best way to challenge stigma and discrimination towards women living with HIV and AIDS is to promote solidarity with, and involvement of, HIV positive people – including women – in all levels of decision making. Although there is a lot of rhetoric about challenging the stigma of HIV, few organisations take this obvious step. All too often positive women are asked to attend meetings as a way of 'setting the scene' by giving a personal testimony, rather than being included from the outset in deciding agendas and taking decisions. Instead, policy-makers should promote the rights of women living with HIV/AIDS by:

- Supporting the capacity building needs of positive women's networks with regard to fund management, strategic planning, and other administrative processes.
- Encouraging more interactive, less formal means of consultation to ensure that HIV positive women have the opportunity to contribute their ideas fully.
- Developing mechanisms to encourage HIV positive women to participate in the electoral process and other political activities.

Bell, E. (2005) 'Advocacy training by the International Community of Women Living with HIV/AIDS', *Gender and Development: 13:3*
http://www.icw.org/tiki-download_file.php?fileId=194

The International Community of Women Living with HIV/AIDS joined forces with the POLICY project with the aim of developing an advocacy agenda on sexual and reproductive health rights, and access to care, treatment, and support for women living with HIV/AIDS in South Africa and Swaziland. The process began with an assessment of the concerns and experiences of HIV positive women, and of the policy and institutional environment. A workshop was subsequently held, involving 45 HIV positive women from Swaziland and South Africa, to discuss the assessment and identify priority issues for advocacy. The concerns raised by the women included: having less decision-making power in sexual relationships than men; having to care for others when you need care yourself; anxiety over disclosure; lack of solidarity among women; and lack of meaningful involvement in policy and programme formulation, and in research into prevention and treatment. The advocacy goals chosen included: to make available alternative technologies which prevent the transmission of HIV while allowing conception; to enable HIV-positive women to adopt children; and to ensure that the property rights of HIV positive women in rural and urban areas are protected.

WomenLead (2006) *WomenLead in the Fight Against AIDS*, The Centre for Development and Population Activities (CEDPA)

http://www.cedpa.org/content/publication/detail/871

Research tells us that women and girls are becoming increasingly infected by HIV/AIDS in countries around the world. But facts and figures don't tell the whole story. This addition of WomenLead presents the personal testimonies of 12 women who are on the frontlines in the fight against AIDS. These women from 10 countries came together for a month-long Women Lead in the Fight Against AIDS workshop, a programme held at the Centre for Development and Population Activities in 2005. One clear message emerges from their stories: around the world, women and girls are the ones bearing the burden of the disease. As one participant from Kenya remarked: "The culture always blames the woman, even if the man brought the disease." The stigma of living with HIV prevents many women from finding out their status, and HIV positive women who do publicly acknowledge their status face discrimination and violence. But the stories also offer hope, highlighting the determined efforts of positive women to combat stigma and discrimination against those living with HIV/AIDS, raise awareness about prevention methods, and mobilise communities to support the care of patients and insist on the availability of treatment and services for all.

8 Tools and guides

ICW (1999) *A Positive Women's Survival Kit*

Survival Kit:

http://www.icw.org/files/20706_ICW_Survival_Kit.pdf (English) (1,300 KB)

http://www.icw.org/tiki-download_file.php?fileId=1 (Spanish)

Fact Sheets:

http://www.icw.org/node/239 (English)

http://www.icw.org/kitdesurviedelafemmepositive (French)

The sexual desires and rights to pleasure of HIV-positive women are often totally ignored. As a result, information which addresses the specific needs of women living with HIV is scarce.
'A Positive Woman's Survival Kit' has been produced by and for women living with HIV/AIDS from all over the world. The first part of the kit focuses mainly on the voices of HIV-positive women and addresses topics such as: dealing with a positive diagnosis; disclosure; staying healthy; pregnancy, childbirth and breastfeeding; communicating with children; relationships; sex and sexuality; grief and loss; sex work; and human rights and HIV. The second part consists of fact sheets which provide information on specific subjects, including: tips for eating well; reducing mother-to-child transmission of HIV; drug use and harm reduction; condoms; and STIs. The kit is also available from ICW in French, Russian, Urdu, Thai, Kiswahili and Portuguese.

EngenderHealth/ICW (2006) *Sexual and reproductive health for HIV-positive women and adolescent girls: manual for trainers and programme managers*. New York and London

http://www.icw.org/files/srh_manual_final%20pdf-Nov-06.pdf (1,000 KB)

Sexual and reproductive rights apply to all individuals regardless of HIV status. Yet more often than not, the rights of HIV positive women and adolescent girls are not recognised or given priority. Health workers need both training and support to eliminate stigma and discrimination towards women living with HIV and to provide quality safe and compassionate care to HIV positive women. In general, there needs to be a greater awareness of the larger social context of issues such as those affecting sexuality, sexual health, access to care, and confidentiality. This manual is designed to provide information and structure for a four-day training and a two-day planning workshop that will enable programme managers and health workers in resource-constrained settings to offer comprehensive, non-judgemental, and quality care and support to HIV positive women and adolescent girls in the local context. The manual also urges male involvement and promotes a holistic approach to integrated SRH counselling and programme planning that links SRH and HIV/AIDS services. The curriculum consists of: an introduction for the trainers; detailed session guides; and appendices containing additional training materials and programming tools.

Southern Africa HIV/AIDS Information and Dissemination Service (SAfAIDS) (2005) *Women's Treatment Literacy Toolkit*

http://www.safaids.org.zw/viewpublications.cfm?linkid=47

In Southern Africa, there are 13 women living with HIV for every 10 infected men, and this gap continues to widen. This toolkit is designed for women and girls in southern Africa who are already HIV positive; who are caring for someone – especially a woman – on HIV/AIDS treatment; who do not yet know their HIV status and would like to know what steps to take if they test HIV positive; and who are potential supporters of other women and girls on, or in need of access to, HIV/AIDS related treatment. It provides information and tools to help women and girls make informed choices about: whether to begin taking treatment or not; what to do when staying on treatment becomes difficult; and how to support other women who are on treatment. The toolkit contains 12 information sheets, on issues such as anti-retroviral medicines and women's lifecycles; prevention and treatment of women-specific opportunistic infections and conditions; safer, satisfying sex for women; and becoming a "Treatment Buddy" for a woman or girl on antiretroviral treatment.

Summerside, J. (2005) *Relationships and Sex: a Guide for Women with HIV,* Terrence Higgins Trust

http://www.tht.org.uk/informationresources/publications/livingwithhivgeneral/relandsexwom341.pdf (420 KB)

Being HIV positive can often make you feel that it's just too difficult to have an intimate relationship with anyone. But you are the same person you were before you became HIV positive; your ability to form relationships need not alter because of HIV. This guide deals with some of the concerns, decisions and choices faced by HIV positive women when it comes to being sexually intimate with another person. It addresses questions like: why do people want to have sex? How is sex different for women after learning that they are HIV positive? Should you tell your sexual partners that you are HIV positive? What are the risks of passing HIV on to someone who is HIV negative? It also provides information on the risk of becoming re-infected with another strand of HIV, becoming infected through oral sex and transmitting sexually transmitted infections.

9 Monitoring change for positive women

ICW and SIPAA (2005) *Positive women measuring change: A monitoring tool on access to care, treatment and support sexual and reproductive health and rights and violence against women,* created by and for women living with HIV and AIDS

http://www.icw.org/files/monitoringchangetool-designed.doc

How can we measure progress on government commitments to positive change for HIV positive women? Fed up with being approached by researchers but never seeing the results, HIV positive women in Lesotho and Swaziland devised a tool that they themselves could use with other HIV positive women to monitor access to care, treatment and support (ACTS); sexual and reproductive health and rights (SRHR); and violence against women (VAW). The tool is comprised of three sections which address each of these issues in turn. Each section contains:

- Questions for HIV positive women, e.g. How far away is your nearest care and treatment service? As an HIV positive woman, do you think you have the right to have (more) children?
- Questions for service providers, e.g. How do you ensure confidentiality for HIV positive service users? What procedure do you follow if a woman who is HIV positive comes to report an incidence of violence?
- Questions for government, e.g. What is the budget for HIV positive women's access to care, treatment and support within the annual budget? How are HIV positive women involved in the consultation, design and implementation of all relevant policies and legislation?

The tool provides a useful framework for bringing diverse groups together - HIV positive women, health providers and government officials - and to aid the latter two groups to think critically about the impact of their actions on HIV positive women. It also provides a valuable opportunity to reduce the isolation faced by the women living with HIV and AIDS, as well as being a chance to highlight issues that often get sidelined in work on HIV. The tool has been adapted for a number of research and monitoring programmes, for example:

- sexual and reproductive rights in South Africa, Namibia and Botswana
- access to care, treatment and support in Namibia, Tanzania and Kenya
- training on monitoring and advocacy with HIV positive Swazi women

De Bruyn, M. (2006) *Fulfilling reproductive rights for women affected by HIV/AIDS.* A tool for monitoring progress toward three Millennium Development Goals, Updated version, Chapel Hill, NC, Ipas

http://www.icw.org/files/Ipas%20MDG-HIV-RH%20monitoring%20tool%208-06.pdf

All local government and NGO programmes targeting HIV-positive women must include HIV-positive women in policy and programme design, monitoring and evaluation. This is just one of the suggested indicators to measure progress on fulfilling reproductive rights for women affected by HIV and AIDS. The 10 simple benchmarks and accompanying questions proposed in this document are designed to facilitate fact-finding exercises and data collection in order to establish a baseline regarding neglected

areas of reproductive health. In some cases, answers can be found simply by reviewing available documents and interviewing staff from organisations involved in HIV/AIDS work. By linking the questions to three of the MDGs - MDG 3 on gender equality and women's empowerment; MDG 5 on maternal health; and MDG 6 on stopping and reversing the spread of HIV infection (and other infectious diseases) – comparable data across countries and time can be collected for presentation at local, national and international forums where HIV/AIDS policies and programmes are developed and reviewed. In 2005, Ipas partners trailed the tool locally in the countries in which they worked and showed that provision of benchmarks, together with some very simple guidance on implementing a data-collection exercise, was sufficient to enable NGO partners in very different countries to collect information on the same topics. The report from these trials is available on the Ipas website:
http://www.ipas.org/english/default.asp
A summary of the report in Spanish is available at:
http://www.comminit.com/la/evaluacion/Evaluacion2005/evaluacion-130.html

Section three: networking and contact details

1 Global

Global Network of People Living with HIV/AIDS (GNP+) P.O. Box 11726 1001 GS Amsterdam The Netherlands Tel: +31 20 423 4114 Fax: +31 20 423 4224 Email: infognp@gnpplus.net Web: http://www.gnpplus.net/cms/index.php	The Global Network of People Living with HIV/AIDS (GNP+) is a global network for and by people with HIV/AIDS. The mission of GNP+ is to work to improve the quality of life of people living with HIV/AIDS.
International Community of Women Living with HIV/Aids (ICW) Unit 6, Building 1 Canonbury Yard 190a New North Road London N1 7BJ United Kingdom Tel: +44 20 7704 0606 Fax: +44 20 7704 8070 Email: info@icw.org or emma@icw.org Web: http://www.icw.org/	ICW works to ensure that the rights of HIV positive women are respected, protected and fulfilled by building the advocacy skills of HIV positive women, providing ongoing support for their advocacy efforts, and supporting HIV positive women to speak in policy forums and conferences.
International Planned Parenthood Federation 4 Newhams Row London SE1 3UZ United Kingdom Tel: +44 20 7939 8200 Fax: +44 20 7939 8300 Email: info@ippf.org Web: http://www.ippf.org/	IPPF works to ensure that poor and marginalised people are able to exercise their rights to make free and informed decisions about their sexual and reproductive health.
International Network of Sex Work Projects P.O. Box 13914 Mowbray 7705 10 Herschel Rd Observatory 7925 Rep. of South Africa Tel: + 27 21 448 2883 Email: secretariat@nswp.org Web: http://www.nswp.org/	NSWP works to promote sex workers' health and human rights. With member organisations in more than 40 countries, the Network develops partnerships with technical support agencies to work on independently-financed projects.
International Council of AIDS Service Organisations (ICASO) 65 Wellesley St. E., Suite 403 Toronto, Ontario, Canada M4Y 1G7 Tel: + 1 416 921-0018 Fax: +1 416 921-9979 Email: icaso@icaso.org Web: http://www.icaso.org/	ICASO works to mobilize communities and their organisations to participate in the response to HIV/AIDS to promote greater involvement of people living with, and affected by, HIV/AIDS in all aspects of prevention, treatment, care and support, and research.

UNAIDS 20, avenue Appia CH-1211 Geneva 27 Switzerland Tel: + 41 22 791 3666 Fax: + 41 22 791 4187 Email: RTdata@unaids.org Web: http://www.unaids.org/en/	UNAIDS, the Joint United Nations Programme on HIV/AIDS, brings together the efforts and resources of ten UN system organisations to the global AIDS response.
United Nations Population Fund (UNFPA) 220 East 42nd St. New York NY 10017 U.S.A. Tel: + 1 212 297 5000 Web: http://www.unfpa.org/index.htm	UNFPA supports countries in using population data for policies and programmes to reduce poverty and to ensure that every pregnancy is wanted, every birth is safe, every young person is free of HIV/AIDS, and every girl and woman is treated with dignity and respect.
United Nations Development Fund for Women (UNIFEM) 304 East 45th Street 15th Floor New York, NY 10017 USA Tel: +1 212 906 6400 Fax: +1 212 906 6705 Web: http://www.unifem.org/gender_issues/hiv_aids/	UNIFEM makes gender equality and human rights perspectives central to its work on women and HIV/AIDS.
World Health Organisation Department of Gender, Women and Health 1211 Geneva 27 Switzerland Tel:+ 41 22 791 3372 Fax: + 41 22 791 4189 Email: rhrpublications@who.int Web: http://www.who.int/gender/hiv_aids/en/	Due to the importance of HIV/AIDS as a public health problem, and the many gender issues that surround it, the Department of Gender and Women's Health has made focusing on gender and HIV a priority.
Global Coalition on Women and AIDS (UNAIDS) Global Coalition on Women and AIDS 20, avenue Appia CH-1211 Geneva 27 Switzerland Tel: + 41 22 791 5412 Fax: + 41 22 791 4187 Email: womenandaids@unaids.org	The UNAIDS-led Global Coalition on Women and AIDS was established in 2004 to respond to the increasing feminisation of the AIDS epidemic and a growing concern that existing AIDS strategies did not adequately address women's needs. A loose alliance of civil society groups, networks of women living with HIV, and United Nations agencies, the Coalition works at global and national levels to advocate for improved AIDS programming for women and girls.

2 Africa

African Council of AIDS Service Organisations (AFRICASO) 9513, Sacre-Coeur 3 Bp: 28366 Dakar-Medina Dakar-Senegal Tel: + 221 867 35 33 Fax: + 221 867 35 34 Email: admin@africaso.net Web: http://www.africaso.net/index.php	AfriCASO is a coordinating and advocacy body with the mission to promote and facilitate the development of the community response to fight HIV/AIDs. AfriCASO is currently represented in 5 African sub-regions and operates through in-country networks or coalitions and assists the development of sustainable organisational structures for NGOs, CBOs and Groups of PLWAs.
East African Network of AIDS Service Organisations (EANASO) Kenya AIDS NGOs Consortium (KANCO), P O Box 69866 Nairobi, Kenya Tel: + 254 2 71 7664 Fax: + 254 2 71 4837 Email: kenaids@iconnect.co.ke	EANASO's represents AfriCASO across the East African sub-region. The network aims to ensure that its members fulfil their roles in complementing Government's AIDS Control Programmes through information exchange, co-operation and coordination of activities to promote effective AIDS programmes and avoid wasting scarce resources.
Network of African People Living with HIV and AIDS (NAP+) PO Box 32717, Lusaka, Zambia Tel: + 260 1 223 191/223 151 Fax: (c/o WHO) + 260 1 223 209 Email: napnzp@zamnet.zm	The objective of NAP+ is to strengthen the regional voice of people living with HIV/AIDS. Its focus is on information sharing, positive living through behaviour change, and promotion of a positive response toward people living with HIV/AIDS in Africa.
Southern African Network of AIDS Service Organisations (SANASO) PO Box 6690, Harare, Zimbabwe Tel:+ 263 4 740610 Fax:+ 263 4 740245 Email: sanaso@mango.zw	SANASO's represents AfriCASO across the Southern African sub-region. The network aims to ensure that its members fulfil their roles in complementing Government's AIDS Control Programmes through information exchange, co-operation and coordination of activities to promote effective AIDS programmes and avoid wasting scarce resources.

3 Asia and the Pacific

Asia Pacific Network of People Living with HIV and AIDS (APN+) 170/71, 22nd Floor, Ocean Tower 1 Sukhumvit 16, Ratchadapisek Road Klongtoey, Bangkok Thailand 10110 Tel:+ 66 2259 1908 - 9; + 66 2259 1910 Web: http://www.apnplus.org/	APN+ was established in response to the need for a collective voice for PLWHA in the region, to better link regional PLWHA with the Global Network of PLWHA (GNP+) and positive networks throughout the world, and to support regional responses to widespread stigma and discrimination. It aims to achieve this by building the capacity of positive people's organisations to represent their constituents and to network effectively, nationally and within the region.

Asia/Pacific Council of AIDS Service Organisations (APCASO) APCASO No. 12, Jalan 13/48A, The Boulevard Shop Office, Off Jalan Sentul, 51000 Kuala Lumpur Malaysia Tel: + 603 4045 1033 Fax: + 603 4044 9615 Email: apcaso@pd.jaring.my Web: http://www.apcaso.org/	APCASO is a network of non-government and community-based organisations that provide HIV/AIDS services within the Asia and the Pacific region. The mission of APCASO is to provide and strengthen the community-based response to HIV/AIDS in the Asia-Pacific regions

4 Europe

BRIDGE Institute of Development Studies University of Sussex Brighton BN1 9RE, UK Tel: +44 1273 606261 Fax: +44 1273 621202 Email: bridge@ids.ac.uk Web: http://www.bridge.ids.ac.uk/ Web: http://www.siyanda.org	BRIDGE supports gender advocacy and mainstreaming efforts by bridging the gaps between theory, policy and practice with accessible and diverse gender information in print and online.
European Network of Positive People (GNP+ Europe) P.O. Box 11726 1001 GS Amsterdam The Netherlands Tel: +31 20 423 4114 Fax: +31 20 423 4224 Email: infognp@gnpplus.net Web: http://www.gnpplus.net/cms/index.php	The GNP+ Europe is currently being restructured. A new coordinated will be appointed from the end of March 2007and more information will be available then. Please contact the GNP+ headquarters in the Netherlands to be informed about developments of the European network.
European Council of AIDS Service Organisations (EUROCASO) Aids Fonds~Soa Aids Nederland Keizersgracht 390-392 1016 GB Amsterdam Contact: Martine de Schutter mdeschutter@soaaids.nl Tel: + 31 20 62 62669 Fax: + 31 20 62 75221 Web: http://www.aidsfonds.nl/	
International HIV/AIDS Alliance, Queensberry House 104-106 Queens Road Brighton BN1 3XF United Kingdom Tel: + 44 1273 718900, Fax: +44 1273 718901 Email: mail@aidsalliance.org Web: http://www.aidsalliance.org/sw1280.asp	HIV/AIDS Alliance takes a gender approach to HIV/AIDS epidemic that acknowledges the role of both women and men in meeting the challenges of HIV/AIDS.

Terrence Higgins Trust 314-320 Gray's Inn Road London WC1X 8DP Tel: : + 44 20 7812 1600 Fax: + 44 20 7812 1601 Email: info@tht.org.uk Web: http://www.tht.org.uk/	Terrence Higgins Trust works to reduce the spread of HIV and promote good sexual health, provide services which improve the health and quality of life of those affected and campaign for greater public understanding of the personal, social and medical impact of HIV and AIDS.

5 Latin America and the Caribbean

Caribbean Network of Positive People (CRN+) PO Box 3353, Maraval,Trindad and Tobago Tel/Fax: + 1 809 622 0176 Email: crnd@carib-link.net Web: http://www.crnplus.org/	CRN+ is dedicated to raising awareness of PLWHA primarily within the Caribbean Basin through advocacy, lobbying and sensitisation strategies. Its main thrust is to improve access to information exchange, advocacy, lobbying and to build capacity among PLWHA in the region.
Latin American and the Caribbean Council of AIDS Service Organisations (LACCASO) ACCSI — Acción Ciudadana Contra el SIDA Av. Rómulo Gallegos. Edf. Maracay. Apto. 21. El Marqués. Caracas 1071. Venezuela Email: laccaso-sr@accsi.org.ve Telfax: + 58 2 235 9215. Contact: Edgar Carrasco E-mail: ecarrasco@accsi.org.ve Web: http://www.laccaso.org/indexeng.html	LACCASO works to control the HIV/AIDS epidemic in Latin America and the Caribbean by promoting coordination, integration and capacity building of civil society organisations, with the purpose to achieve an articulated and effective community and multi-sectorial response to the epidemic.

6 North America

GNP+ North America GNP+ NA regional secretariat 1534 16th Street, NW, Suite 200 Washington, DC 20036 Tel: + 202 332 2303 Fax: + 202 332 7087 Email: info@gnpna.org Web: http://www.gnpna.org/	GNP+NA works to improve the quality of life of people living with HIV/AIDS by creating and sustaining an active North American network of PLWHA's working regionally to address the global pandemic.
National Association of People with AIDS (NAPWA) 8401 Colesville Road Suite 750 Silver Spring, MD 20910 Tel: + 240 247 0880 Fax: + 240 247 0574 Email: info@napwa.org Web: www.napwa.org	NAPWA is a membership organisation that advocates on behalf of all people living with HIV and AIDS. It promotes meaningful involvement and leadership among people living with HIV and AIDS through regional trainings, which include the Leadership Training Institute and Helping Communities Build Leadership.

North American Regional Secretariat of AIDS Service Organisations (NACASO) C/O Canadian AIDS Society 309 Cooper Street 4th Floor Ottawa, Ontartio Canada, K2P 0G5 Contact: Shaleena Theophilus Tel: + 1 613 230 3580 Fax: + 1 613 563 4998 Email: shaleena@cdnaids.ca Web: http://www.cdnaids.ca/	The objective of NACASO is to promote awareness of international issues within North America. ICASO's North America Regional Secretariat is hosted by the Canadian AIDS Society.
WORLD (Women Respond to Life-threatening Diseases) 414 13th Street, Oakland CA 94612, USA Tel: + 1 510 986 0340 Fax: + 1 510 986 0341 Email: nrodriguez@womenhiv.org Web: http://www.womenhiv.org/	WORLD works to provide support and information to women with HIV/AIDS and educate and inspire women with HIV/AIDS to advocate for themselves, one another, and their communities.