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"Oh! This one is infected!": Women, HIV & Human Rights in the Asia-Pacific Region

By

By Susan Paxton[1] and Alice Welbourn[2], with P Kousalya[3], Anandi Yuvaraj[4],

Sapana Pradhan Malla[5] and Motoko Seko[6]. [7]

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[1] APN+ Advisor, Australian Research Centre in Sex, Health and Society, La Trobe University, Australia
[2] Chair, Board of Trustees, International Community of Women living with HIV/AIDS (ICW)
[3] ICW South Asia Trustee and Director, Positive Women's Network, India
[4] International HIV Alliance, India
[5] President, Forum for Women, Law and Development (FWLD), Nepal
[6] UNIFEM Programme Specialist, Gender and HIV/AIDS, Asia-Pacific region

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SETTING THE SCENE - THE GLOBAL BACKGROUND

> ***"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"***
> **WHO Constitution, 1946**

By the end of the twentieth century, AIDS was the fourth leading cause of death in the world, after lower respiratory infection, heart disease and stroke. Women are more than four times more vulnerable to HIV infection than men are, women less than 20 years old are up to ten times more vulnerable and women are significantly more likely than men to experience AIDS-related discrimination after infection. The response to HIV and AIDS to date has failed to address adequately women's inability to prevent themselves from becoming infected, resulting in a thriving epidemic and huge populations of HIV-positive women who live in unsafe and undignified conditions.

The Asia-Pacific region is no exception. This paper sets out to explain the varied reasons why a significant majority of women in the region are disproportionately at risk of infection, documents specific examples of discriminatory attitudes and actions against HIV-positive women in the region as a result of their HIV status; and concludes with recommendations of action by and for all levels of society to counteract these human rights violations.

Determinants of health are multi-faceted. Societal and cultural double standards for men and women are barriers to health care efforts and the oppression of women has led to denial of their rights. Women's lower social, political & economic status is fundamentally linked to negative health outcomes, particularly in relation to HIV/AIDS. Society has constructed profound psychological and social differences based on gender, yet the response to HIV/AIDS fails to recognise these differences. Women are still seen primarily in their reproductive role, whilst men are seen as the monetary providers, and thus retain physical, social, legal, religious and medical control over women's lives. Because of this imbalance of power, public health interests are usually determined by men, driven by economic rationalism and often override women's rights. Compare, for instance, the finances invested in AIDS vaccines versus female-controlled microbicides; and the funds invested in drug trials of white males. Prevention of mother-to-child transmission programs improve quality of life of a child but often overlook or neglect the health of the mother; and abortion is often advocated for positive women who may want a child. Interventions target women in relation to either men or children and do not recognise women as separate entities in themselves. These interventions are also very often judgmental.

Women carry a "triple jeopardy" of AIDS: as people infected with HIV, as mothers of children infected, and as carers of partners or parents with AIDS (or, in the case of increasing numbers of grandmothers, as carers of orphans). Care, traditionally one of women's many responsibilities within a family, is provided free, but has a hidden cost. When women care for others, their labour is lost, which has a huge impact on the wealth and therefore the health not only of themselves, but also of the whole household. In the case of girls, they are often removed from school to care for sick relatives. This is also a huge economic and social loss, both for them and

for their future families. HIV/AIDS is thus contributing to the acceleration of feminised poverty across the world and the Asia-Pacific region is no exception.

WOMEN'S GREATER VULNERABILITY TO HIV INFECTION

Latest UNAIDS figures (December 2003) indicate that 9.5 million people are living with HIV/AIDS in the Asia-Pacific Region. For most women in the region, the means of transmission is overwhelmingly heterosexual and, for a range of reasons, infection rates in many countries are escalating more rapidly in women than in men. If trends in Asia follow those of Africa, then it will be only a matter of time before the overall percentage of infected women and girls in Asia overtakes that of men and boys. The reasons for women's and girls' greater vulnerability to HIV infection are summarised below:

Biological Reasons

- There is more virus in sperm than in vaginal secretions; therefore women are more likely to be infected by men than men infected by women.
- The vagina has a large mucosal surface; any microlesions caused during intercourse may be entry points for the virus; young women are even more vulnerable because the mucosal lining is thinner and less mature.
- Coerced and violent sex increases the risk of microlesions, especially since condoms are unlikely to be used in such circumstances.
- The presence of untreated sexually transmissible infections (STIs), which may cause open sores and which women may not notice, increases risk of exposure to HIV.

Economic Status

- Women are likely to be less educated than males, more overworked and underpaid.
- Women are expected to work in the home and are often discouraged from going out to work, so they are more financially dependent on men.
- Women have few opportunities to engage in waged labour and so have limited financial survival skills if the primary breadwinner is sick.
- If women work outside the home, many are forced to become transient workers.
- Many women have to exchange sex for material favours for daily survival.
- Poor nutrition increases vulnerability to HIV infection. (In India, nearly 50% of all married women suffer from anaemia (UNIFEM 2002)).
- Women are often not permitted to own property or to legally inherit ancestral properties or possessions. Though recent legal interventions in some countries (such as the eleventh amendment to the Country Code in Nepal and the amendment in the Hindu Succession Act in a few states of India) have given them legal ownership and inheritance rights, these rights are seldom upheld in practice, hence women's status remains the same.

Social and Cultural Norms

- Women are not expected to discuss or make decisions about sexuality. "Good" women are expected to be virgins before marriage and are expected to be "ignorant" or uninformed of any matters relating to sex, including their own sexuality.
- If women refuse sex or request condom use, they risk abuse.
- Violence against women (especially domestic violence) leads to forced sex (thus increasing microlesions).
- Marital rape is not recognised as a crime in many countries (and in no countries in South East Asia), so marriage condones non-consensual sex between a man and his wife at any time.
- For men, multiple partners and sex outside marriage are widely culturally accepted.
- Women are expected to have relations with or marry older men, who are more sexually experienced, and more likely to be infected.
- Arranged marriages, particularly among relatives, without the bride or groom getting to know one another first, are a norm in rural India. (In India, 60% of married women become mothers before the age of 19 (UNIFEM 2002)).
- Marriage is strongly associated with reproduction and creating a family, and there is strong pressure on young, newly married women to have children
- A woman's status greatly improves if she becomes a mother.
- The majority of non-literate people in Asia are women. This limits women's ability to access information for HIV/AIDS prevention, care or treatment

The following remarks are from HIV-positive women who took part in the ICW study in Thailand, "Positive women: Voices and Choices". They clearly illustrate the importance of, and societal pressure on women to have children, and the conflict that results from a desire for children and a positive diagnosis:

"If we were childless, our family wouldn't be perfect. I mean, there was conflict. He wanted to see what his child would look like. I had to take a risk. If the baby is HIV-negative, our lineage goes on. If we were childless, there would be conflict." (Woman in the Northeast, aged 27)

"I wanted to make the family perfect. If we had no child, he wouldn't stay with me and I would be alone, lonely." (Woman in the Northeast, aged 31)

"Having a child is necessary for those not infected [with HIV]. But the infected, they shouldn't see it as necessary. I mean, a family must have a mom-dad-kids thing in order to be perfect. The child is the centre, the heart, of a family." (Woman in Central Region, aged 36)

Programmatic Vulnerability

In health services across the region – and indeed around the world - organisational structures and the development of policies are often gender-blind and even uphold and exacerbate discrimination against women. Mann and Tarantola (1996) refer to this as "programmatic vulnerability" of women. Most of the senior management positions are held by men and most doctors are men who have not considered the gender dimensions of health care, nor explored their own issues around sexuality or their own vulnerability to HIV. Healthcare policies tend to be formulated almost exclusively by men. Thus, to take one example, female controlled barrier methods such as the female condom have received relatively little research support. Similarly research on antiretroviral drugs has focused mainly on men, and has not addressed, for example, potential gender differences in drug tolerance. Female health service staff are often placed in junior, poorly respected front-line positions, as nurses, cleaners, or in other auxiliary positions, with long hours, poor pay and little prospect for career development. Although they may have many insights into how services may be better run, based on their direct working experience, their opinions are not sought or welcomed.

OTHER SPECIFIC ISSUES

Women and condoms

Women's lack of socio-economic power facilitates the spread of HIV. "ABC" messages of "abstain, be faithful or use condoms" fail to recognise the context of women's lives.

> The Behavioral Surveillance Survey 2, conducted by the National AIDS Control Organisation in India, showed that 80% of women currently living with HIV/AIDS had only one sexual partner and contracted the virus from that partner. The majority of women did not perceive that they were at risk of contracting HIV and, even if they had perceived the risk, did not have the skills to negotiate condom use with their partner; in fact the majority of women did not know that condoms prevent infection.

Most women have no control over when, with whom and in what circumstances they have sex. Condom use is particularly problematic. If women suggest using condoms, their partner often assumes that the woman has been unfaithful. Condoms are not under women's control and some women are threatened with violence and rejection if they insist on condom use. It is not culturally acceptable in most Asian societies for women to purchase or to possess condoms. In China, if a woman is found with a condom in her bag, she can be arrested on suspicion of being a sex worker. In Nepal, female sex workers reported many cases of police abuse because of carrying condoms with them (FWLD, 2003b). In India, people involved in sex education work, especially field workers and social workers, face problems from law-enforcing agencies if condoms are found in their bags. Thus reaching and educating not only men, but also women to accept condom use is challenging. Cost is also an issue. For instance, the female condom was launched in New Delhi in 2004, at a cost of Rs 45 or nearly one dollar each. Although the price

is expected to halve in coming months, NGOs say that anything above Rs 3 is prohibitively expensive for most women.

Women and drug use

In some parts of Asia, sharing injecting equipment is a significant mode of HIV infection. Needle exchange programs have shown success in curbing the spread of the epidemic amongst injecting drug users but tend to be male-focussed and deny the reality of women's lives, particularly those of women who are partners of injecting drug users. Many female partners of drug users, whether they are themselves drug-dependent or not, may be exposed to gender violence and exploitation by their partners, who may force them to sell sex to others. Many people assume that women using drugs are also engaged in commercial sex to finance their drug use. Thus female drug users are doubly discriminated against, by their communities and health service providers, because of negative attitudes towards sex workers and drug use.

Women and sex work

HIV-positive women who are sex workers or who sell sex but do not identify themselves as sex workers are especially at risk from discrimination and violation of their rights because of the moral judgments imposed on them by society. Studies conducted in Tamil Nadu and Andra Pradesh States in India show that only 20% of sex workers use condoms with their non-paying (mostly regular) partners. (Behavioural Surveillance Survey, NACO, India). This finding echoes similar findings from elsewhere in the world. Sex workers are therefore at increased risk of HIV-infection from their regular partners.

> *"I worked in both a cocktail lounge and a massage parlour which provided sexual services. I was married twice. My first husband worked in the same place as me. He was the one to infect me with HIV and he died later. I used a condom when I had sex with a guest. It was safety first."*
> (Thai woman, aged 30, Positive Women: Voices and Choices)

In a study conducted in Nepal (FWLD, 2001), out of a total of 100 respondents only 44% of women said their partner used a condom while having sexual intercourse. Of these, 84% stated that their partner used it for the purpose of family planning and not for safer sex; 49% said that they have sex with their partners because they perceive it as a responsibility and duty. When discussing the refusal of sexual intercourse by women, 37% of respondents stated that their partner's reaction includes arguments, scolding, beating, expressions of suspicion towards their wife, threats that they will take a second wife or have an extramarital relationship. Nine percent of women complained that their partners consider sexual intercourse to be their right. In Nepal, the rape law exempts marital rape as a crime; the definition of rape is non-consensual sex with a person "other than one's own wife". After a case filed in the Supreme Court by FWLD in May 2002, the court interpreted marital rape as a crime and issued a directive to the government to introduce an appropriate bill into parliament. To date, no initiative has been taken towards enacting such legislation.

In Asia, discrimination against sex workers is so strong, even from other women, that many HIV-positive women will not go to an STI clinic for fear of being labelled as a sex worker. Because HIV prevention strategies focused initially on sex workers, HIV-positive women face strong discrimination and assumptions that they must have been sex workers.

The situation facing women and girls who are trafficked for sex work is in many ways even worse, since they are often taken far from home to live and work in situations where they have no one to turn to who can speak their language.

Different sexual orientations
Lesbians, bisexual women or transgender persons are especially vulnerable to human rights violations because of judgmental attitudes in society. If they are HIV-positive also, they may face even more discrimination. The specific issues facing these women, although beyond the scope of this paper, are of concern and need particular recognition and support.

AIDS-RELATED DISCRIMINATION

Ante-natal testing
Along with the explosion of HIV has come increased discrimination, particularly against women found to be infected with HIV. A young woman is often the first person in a family to be tested, particularly with increased routine HIV screening during pregnancy. (In many instances testing happens without the woman's informed consent and without pre- or post-test counselling.) "Good" women in Asia are not supposed to have pre-marital or extra-marital sex and are supposed to enter marriage as virgins, with no sexual knowledge. For men, the rules are not so strict. Although most women contract HIV from their monogamous long-term partners, it is often assumed that it is the woman who has been unfaithful, so they are seen as "vectors" of the virus, blamed for bringing it into the family and subjected to violence and abuse by their spouse or in-laws.

Of the women who participated in the ICW Thailand study, 52% discovered their positive status as a result of having their blood tested in antenatal clinics, during treatment for other medical conditions, or because it was required by their employers. Often the women did not know that they had been tested for HIV until they were given their results:

"When I was pregnant and went for antenatal care, I was told to have a blood test. They did not tell me what the test was for. Every woman who came to the clinic had to have their blood tested. They did not explain at all what kind of test they were doing. I realised it was the AIDS test when I received the results." (Thai woman, Central Region, aged 29)

"I was cheated by a doctor to have had an exam. The doctor said to my husband that it was the virus, and asked my husband to take me for an exam too. I consider this as cheating because they did not tell the truth. They neglected my

personal rights. If someone learns about it, and they tell others, it may have an ill effect on my work. I may be unemployed because society still cannot accept people infected with this disease." (Thai woman, Central Region, aged 37)

"While I was working in this factory, I had a blood test. I was not told that it is the AIDS test, but it was. They just said it was a physical check-up, health check-up." (Thai woman, Central Region, aged 26)

"At that time I knew that I've got AIDS because my husband died of AIDS. I had already gotten a job... but my boss wasn't sure if I had HIV and wanted me to leave my job... He forced me to have blood taken."
(Thai woman, Central Region, aged 28)

"The time I was hit by a car and admitted to hospital, they took my blood for a test. They did not say for what test. I kept quiet because I was a patient. Then they told me that I was positive for a blood test, but not what kind of blood test. I knew nothing. (Thai woman, Central Region, aged 32)

Health providers' attitudes
Many women experience discriminatory attitudes from health care workers, particularly in relation to their choices around pregnancy.

"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, aged 25, Positive Women: Voices and Choices)

"Some health personnel even threaten the women that if they are not sterilised, they will not receive powdered milk for their babies."
(ICW, Thailand Positive Women: Voices and Choices Report)

Findings from twenty-six key informant interviews, conducted in India and Thailand for a study by Ipas (de Bruyn et al, 2002) indicate that women diagnosed with HIV have very limited reproductive choices; decisions are often made by the health care provider, the husband or the in-laws, often resulting in the woman resigning herself to an unplanned or unwanted pregnancy, or a coerced abortion and sterilisation. This is despite the fact that abortion is still illegal in many countries in the region (eg: Indonesia, the Philippines, Laos, Myanmar) and therefore has to be carried out in ways which can severely endanger women's lives (McConville, 2002). Respondents in the Ipas study felt that community attitudes towards women with HIV who become pregnant are that the women are irresponsible and should have an abortion, and be sterilised. Attitudes of health care workers are often patronising and judgmental and any

counselling is usually directive. Women with HIV reported general reluctance and frequent refusal by health care workers to provide invasive treatment to help with childbirth. If women refuse to do what they are told, and go ahead with the pregnancy, they often find themselves giving birth without skilled attendants at hand, thereby placing themselves and their newborn infant at greater health risk.

> *"One of our friends opted for medical termination of a pregnancy from a government hospital. She was 16 weeks pregnant and this was her third abortion. She was her husband's second wife. They had never used a condom and the pregnancies were unplanned. When she conceived a third time she was afraid to visit the health care providers because she knew they would scold her for coming back again. Over the past two years her husband often fell sick and most of her time was spent in hospitals caring for her husband. When she sought the doctor for terminations she was advised to undergo sterilisation, which she was not willing to do. I took her to the gynaecologist who said, "You know she is coming for the third time. I have been telling her to get sterilised and I am doubtful; how did she get pregnant when her husband is so ill and bedridden?" I was shocked to hear this. I said she has the right to decide and only she knows her situation; nobody can judge her. The government hospitals refused on the grounds that she was in her fifth month of pregnancy. While she was shunting between hospitals her husband passed away. She had no choice other than continue with the pregnancy, which she was not prepared for. She gave birth to a girl and is staying with her natal family now. She had no access to condoms and no supportive environment in which to make any decisions."* (A.Yuvuraj, Personal communication)

Discrimination by health care workers, especially in relation to the prevention of parent-to-child-transmission, was echoed repeatedly in a study conducted by Centre for Advocacy and Research, the Positive Women's Network of India, and UNIFEM (2003). Discrimination from service providers was also experienced by women in Thailand who sought HIV-related treatment and family planning services:

> *"I'd been to a hospital, and was told to have an IUD fitted. When I went for the fitting, they did not allow me to use it because I didn't live permanently with my sex partner. They asked me why I should bother using it. Then, when they checked my medical file and learned that I've got HIV they said Oh! This one was infected! The HIV-infected should not use it. They said this as if those who were infected should not be given any services. Eventually, I gave back the IUDs."* (Thai woman, aged 39, Positive Women: Voices and Choices)

Confidentiality from health service providers also emerged as an issue:

> *"It happened that personnel at the health care centre, a nurse, said somewhere around my neighbourhood that… 'Yes, yes, this girl (meaning myself) really has HIV'. I was very angry. She shouldn't have talked about me like that, but she'd already said it."*
> (Thai woman, aged 29, Positive Women: Voices and Choices)

In Nepal, medical practitioners acknowledged that they discriminate against patients infected with HIV/AIDS because of the fear of infection. They also expressed the view that HIV-positive patients must be segregated from other patients (FWLD, 2002).

Many health care workers are themselves living with HIV and often have little access to information, support or services – or awareness of their own status. Many frontline women workers are also over-stretched and exploited by their male managers (Khanna et al, 2002) and often lack basic information about HIV transmission. In Pakistan, for instance, it is a common practice in rural areas for health workers to inject patients with unscreened blood in order to boost energy levels. In India, a parliamentary reply in February 2004 reported that 68.8% of injections in government clinics are "unsafe" (http://164.100.24.208/lsq/quest.asp?qref=70356). Health staff need proper information and support to cope with their own realities and those of their clients.

Discrimination within families and communities
A documentation of AIDS-related discrimination in Asia conducted by APN+ in 2001-2 found that HIV-positive women are significantly more likely to experience discrimination in the family and the community than are men. The study interviewed over 750 HIV-positive people in India, Indonesia, Thailand and the Philippines; the major determinant of AIDS-related discrimination was sex of respondents.

Differential discrimination experienced by HIV-positive men and women
Key findings from APN+ study

Questions Asked	Affirmative responses (%)	
	Males (n=394)	**Females** (n=348)
Has anybody been told about your HIV status without you wanting them to know?	33.5	35.3
Have you ever been ridiculed, insulted or harassed because of your status?	20.3	31.3*
Have you ever been physically assaulted because of your status?	2.5	6.3*
Have you ever been refused entry to, removed from or asked to leave a public establishment due to HIV?	2.8	8.6*
Have you been forced to change your place of residence because you are known to be HIV-positive?	6.3	12.4*
Have you ever been excluded from social functions due to your HIV status?	8.6	16.1*
Since your diagnosis have family members excluded you from usual family activities?	10.9	17.8*
Have you ever lost financial support from family members due to your HIV?	4.6	10.6*
Has anybody ever advised you not to have a child since you were diagnosed as HIV-positive?	17.8	45.1*
Have you ever been coerced into an abortion or sterilisation because of your HIV status?	-	11.5
Has your child (or children) ever been involuntary taken away from you because of your HIV status?	2.0	2.9

* indicates significant difference in proportions between male and female respondents ($\rho<.05$)

Overall, 45% of females (but only 18% of males) were advised not to have children after their diagnosis and 12% of women were coerced into an abortion or sterilisation because of their HIV status. Some women lost custody of their children. Ten per cent of respondents (females 12%, males 6%) were forced to change their place of residence because of HIV and many had to change their home more than once. In India, eight per cent of respondents had been physically assaulted because their HIV status had become public knowledge.

The situation for single and widowed women is even worse; they are particularly vulnerable to human rights violations, including physical assault from family or from members of the community. Widows and single women disproportionately head poor households affected by HIV and bear the brunt of AIDS-related discrimination.

Research conducted in India by the Positive Women's Network, and the Centre for Advocacy and Research included 21 in-depth interviews with HIV-positive women (CFAR and PWN,

2003). The findings indicate the following key areas of concern with regard to the attitudes towards and treatment of HIV-positive women:

- Stigma, Discrimination
- Violence
- Livelihood and Property
- Security
- Health care
- Information
- Support Systems
- Economic difficulties resulting from having a male family member with AIDS
- Negotiating capacity

Similar findings emerged from the ICW Positive Women: Voices and Choices research with 320 HIV-positive women in Thailand. The key findings of this research highlighted a broad range of concerns, including:

- HIV status disclosure and acceptance,
- Motherhood, pregnancy and child-rearing,
- Sexual relationships and spouses,
- Reproductive health services, including abortion, sterilisation, social welfare and other support,
- Sexual practices, STIs, and family planning after HIV diagnosis,
- Blood-screening,
- Involvement in clinical trials,
- Income generation and support,
- Participation in HIV-support groups, and in support and assistance programs, including access to information

> *"The doctors should voluntarily give us information on how to behave after getting this disease. As far as I'm concerned they just tell you how to prevent getting the disease, not what to do about it once you are infected."*
> (Thai woman, aged 37, Positive Women: Voices and Choices)
>
> *"I decided to have a check-up at one of the government hospitals. After the blood test, a nurse asked me to go into a room, and she said that I'll certainly die. She asked me if I know how much the virus spreads yearly, and she said that around 60% already died with AIDS. I was so scared …a nurse said 60% which is over half, so I will probably die in the next few years… my feeling was so bad."*
> (Thai woman, aged 37, Positive Women: Voices and Choices)

Self-discrimination
In response to the discriminatory attitudes that women face on diagnosis, many hide away. This internalised ostracism becomes stronger once HIV symptoms become more obvious. Issues of body image are especially important to women, as a result of gendered stereotypes promoted in the media of how women *should* look. Thus advanced HIV-related illness can be especially psychologically debilitating.

> *"Give me any job that will not let me mingle with people, any job that will not allow me to meet people; a job in which I can work behind the scenes, such as washing up dishes, anything, the kind of job where I do not have to see people. They may not like me. I do not want to face other people's eyes when they look at me. Any job that I can work behind the scenes; no one can see me; or a job that we [HIV-positive people] can work together among us"*
> (Thai woman, aged 25, Positive Women: Voices and Choices)

Discrimination from NGOs and funders
HIV-positive women also face discrimination from funders and NGOs if they decide to form themselves into groups to develop their own response to the pandemic. HIV–positive women often find that they are not able to access funds to start networks or implement their own initiatives. Programs that are funded are very service-oriented and do not focus on building the skills of the women concerned. Though there is talk of the "GIPA Principle" (commitment to the greater involvement of people living with HIV/AIDS in the response to HIV/AIDS) the reality is very different.

Women, HIV and ethnicity
Ethnicity is another factor that exacerbates HIV-vulnerability. In Australia, the rate of HIV in the indigenous population in 2002 rose sharply compared to that within the non-indigenous population. Within the indigenous population women represent 36% of overall HIV infections, compared to 10% within non-indigenous people (Bev Greet, Personal communication[8]). This is not unexpected, given the poorer socio-economic and health conditions and poorer access to education, employment, health and other services experienced by indigenous Australians. Similar quality of life issues exist in indigenous communities elsewhere in the world and HIV prevalence amongst women in indigenous communities in other parts of the Asia-Pacific region may be higher than in the wider population.

Comparisons with elsewhere
There are marked similarities in the recent ICW Positive Women: Voices and Choices Research Studies conducted by and with HIV-positive women in Zimbabwe (Feldman, Manchester and Maposhere 2002), in francophone West Africa (forthcoming) and in Latin America

[8] For further Australian data see www.med.unsw.edu.au/nchecr

(forthcoming). This underlines the urgent and critical importance to the region of adopting a gender-based response to these findings. The circumstances of the vast majority of HIV-positive women and girls in the region are undoubtedly exacerbated by the combination of their HIV status and their gender.

THE NEED FOR A GENDER-BASED RESPONSE

Gross inequality between males and females denies women the ability to protect themselves from infection, increases discrimination against them when they have HIV and drives the epidemic. HIV disproportionately affects women:

- they are highly vulnerable to infection;
- they are often blamed for spreading HIV;
- they bear the psychosocial and physical burden of care;
- they face the greatest levels of AIDS-related discrimination

Programs to respond to human rights violations of people living with HIV need to be gender-sensitive. They need to be designed to challenge and transform those cultural norms that are harmful, enhance women's participation in decision-making and remove the social and cultural barriers to women's improved health and dignity.

International instruments of accountability
Trying to operationalise a gender-based perspective to overcome discrimination is problematic. Many countries are signatories to various covenants and declarations aimed at ensuring that the rights of all women are upheld (some key ones are set out below), but there is a need to strengthen the enforcement mechanisms of the treaty bodies that monitor compliance with these international conventions.

Some key declarations in support of women

a) The 1966 International Covenant on Economic, Social & Cultural Rights explicitly names the right to the highest attainable standard of health, and to enjoyment of the benefits of scientific progress. Signatory states have a duty to promote women's health services and to prevent or remove the barriers to women maintaining physical, mental & social well being.

b) The 1979 UN Convention on the Elimination of All Forms of Discrimination Against Women aims to prohibit discrimination and bring gender equality, and also to ensure equal access to health care services. It is an international legal instrument obliging respect for and observance of the human rights of women and is now ratified by 175 countries. The CEDAW Committee has also adopted specific General Recommendation No. 15 for avoidance of discrimination against women in national strategies for the prevention and control of acquired immunodeficiency syndrome (AIDS).

c) The 1993 UN Vienna Declaration calls for the elimination of violence against women in both public and private life. This is the first time that an international treaty recognised and responded to domestic violence. However violence continues to be prevalent, and greater efforts are needed to ensure countries comply with their agreements to stop domestic violence.

d) The 1994 International Conference on Population and Development signed in Cairo by 184 governments placed women and their reproductive rights at the top of the international health agenda. This was a critical shift of focus towards improving women's quality of life, and was intrinsically tied to the global development process.

e) The 1996 International Guidelines on HIV/AIDS and Human Rights adopted by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United Nations Office of the High Commissioner for Human Rights urges States, in collaboration with and through the community, to promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

The promotion of women's health and dignity depends on the upholding of *all* human rights, including the rights to employment, to education, to information, to sexual and reproductive choice and also women's rights to property ownership.

However, it is not legal processes or polices alone that change harmful traditional norms and create a culture of respect for women, but these in combination with actions at all levels of society, in order to ensure that policies are known and translated into practice.

RECOMMENDATIONS: PRACTICAL WAYS FORWARD

Below are some of the many practical contributions that different sectors of society can make, in order to effect changes in current attitudes and practice, and begin to make a meaningful shift towards upholding the rights of HIV-positive women and girls in the Asia-Pacific region. Both policies and practices should provide access to education, information, health care, safe paid employment, legal support, proper nutrition, security, access to social services and to decision-making powers for women.

1. Political Leadership

1a *Governments* can provide political leadership to influence strongly women's ability to attain ***gender equity*** and facilitate rapid change. Governments should be pressured to acknowledge the importance of treating women with dignity and respect, and be made to uphold all treaties and conventions related to discrimination of women. One part of inspired leadership is increasing the

proportion of elected female representatives to the parliaments of the region; another is ensuring that all legislation is reviewed and updated effectively to address the vulnerability of women and protect the rights, dignity and interests of all HIV-positive people. It is also vital that all Government departments are sensitised to the issues and work in coordination to make a difference. All governments should introduce their own HIV workplace policies and fully support any parliamentarians who are ready to disclose their HIV status or discuss their support for relatives with HIV. Such public disclosures can make huge steps in terms of public awareness of the issues and public rejection of discrimination.

Specific areas of law that could and should be addressed urgently to uphold women's sexual and reproductive rights:

- *Marital rape should be recognised as a crime and treated accordingly.*
- *HIV-positive women should have the right to have children when they want to, and should be supported to do so, without judgment. (This means that any HIV/AIDS laws, such as that in Cambodia, that criminalises any person who, while aware of having HIV, transmits it to others, need to be reviewed. While such laws may have been designed to protect women from men who knowingly pass the virus on to them, it can - and has been - used in judgment against women, if they wish to have a baby.)*
- *HIV-positive women should have the right to have an abortion if they want to, and should be fully supported in their decision, without judgment. They should be given access to full, unbiased and correct information and should not be pressurised either to continue with a pregnancy or to terminate it. This should be the woman's choice.*
- *Sterilisation of HIV-positive women should be outlawed unless each woman gives her full, informed and unpressured consent.*
- *HIV-positive pregnant women should receive ARV drugs not only to protect the HIV status of their children, but also in their own right, to maintain their own health after the birth of their child.*

Women need ***physical and material security***, independent of men, and power to control their lives; government leaders can take the lead on this. It implies a profound shift in social and economic power relations between men and women. Action must start through increased educational and employment opportunities for women, including free education, micro-financing and women's property ownership schemes, and the repeal of discriminatory laws and practices against women. Women and girls who are in danger of being trafficked, as well as those who have already been trafficked, especially those who are HIV-positive, should be supported to find alternative options for education and/or employment with dignity. It is also essential that boys are taught, from an early age, the importance of women's contribution to society and the importance of advancing and upholding women's rights within society. Rights and power should not be seen as something limited and finite, which have to be taken away from men, but rather as qualities of life which, if shared, create advantages for *everyone* in society.

1b *Faith-based organisations* can also provide significant leadership, given the huge numbers of active worshippers of many different faiths across the region. Faith organisations already do much to provide care and support for HIV-positive people in the region. However, there is also scope for them to take a more public, political stance. The power to influence public opinion of prominent faith leaders who stand up and speak in support of the rights and dignity of HIV-positive people, and especially in support of the rights and dignity of HIV-positive women cannot be underestimated. The recent inter-faith pledge made by representatives from several different South Asia countries concerning attitudes towards and involvement of HIV-positive people in prevention, care and support programs across the region, is a welcome step.

1c *The business community* also can take a strong role in political leadership, through the introduction of positive and gender-equitable HIV-workplace policies and HIV-awareness programs for all staff, from the directors and their personal partners - outwards. Most paid workers are men: if they are encouraged and supported at work to consider HIV, violence against women and related topics in a gendered framework, opportunities are created for them to take responsibility for their actions sooner, to be tested earlier, to start to use condoms earlier, for them to stay healthy for longer, to remain in paid employment, and to start to work *together* with their partners to support their families longer. Initiatives from some international groups, such as Standard Chartered Bank, or national employers, such as the gender equity zone of the Indian Railroads, are welcome in this respect.

1d *UN bodies, the World Bank and bi-lateral donors* also have a key role to be play. Important new global collaborative initiatives, such as the UNAIDS Global Coalition for Women and AIDS provide key opportunities for UN bodies, the World Bank and bi-lateral donors across the region to promote and insist on gendered mainstreaming of HIV across all sectors of their organisations' work, to include the knowledge, experiences and views of networks of HIV-positive women and their partner organisations in their policy work, and to promote similar positive practices with governments and other partners across the region. There is a particular opportunity for UNAIDS and UNIFEM jointly to develop a knowledge base for good practice to share with their UN colleagues in the region. There is also the opportunity for the World Bank to ensure that it actively funds, promotes and operationalises policies and activities which ensure gender equity and solidarity with HIV-positive women in particular.

2. Radical changes to formal health service policy and provision

2a *Health care staff should provide adequate and non-judgmental information and access to services* to enable all women – and men - to make informed reproductive health decisions. No women should be tested without their voluntary, informed consent. Mandatory testing of pregnant women must stop immediately and be replaced, where possible, with voluntary *couple* counselling and *couple* testing. Moreover, there is also a need to address the problem of poverty, which denies most women access to health services. Considering that pregnancy is the *only* opportunity for many poor women in the region to visit a health care facility, innovative approaches to the dissemination of good HIV-related information must be explored. In India, for instance, the current focus with regard to the health of HIV-positive women is only through prevention of parent-to-child transmission programs. This needs to change, and all other health

departments must be willing to provide quality health care to HIV-positive women and girls. Holistic interventions for women are long overdue.

2b *Equitable access to barrier methods is required.* Health workers need to provide women and girls with an adequate and affordable supply of barrier methods. A cheap, safe, effective HIV-prevention method that is under women's control is essential. The female condom is much more acceptable to women than was originally anticipated but it is less readily available and considerably more expensive than the male condom. Subsidised distribution and promotion of female condoms is needed so they are accessible. The desire and cultural expectation of women to have children must be addressed via a microbicide that is not also a spermicide. Such a development ultimately requires massively increased political will and investment in international research.

2c *Equitable access to ARVs and drugs for opportunistic infections is urgently needed.* HIV-positive women are often carers and when they die, they usually leave behind orphans who are at increased risk of contracting HIV. It therefore makes not only humane but also strong economic sense to keep mothers alive. Generic triple combination antiretroviral drugs to manage HIV infection (ARVs) cost approximately US$1 per day. They are available to less than 10% of people with HIV worldwide. Most people with opportunistic AIDS-related illnesses have no access to the most basic and cheap medications such as fluconazole or cotrimoxazole. WHO are attempting to provide 3 million people with antiretroviral drugs by the end of 2005. But many countries urgently need to improve their basic health infrastructure in order to monitor the distribution and use of increased access to these drugs over the next few years. Programs should focus on improving access to drugs for people already diagnosed, and improving voluntary counselling and testing facilities It is dangerous if these programs are driven by targeted numbers of people, as this may lead to coerced testing, which in turn will lead to increased instances of subsequent human rights violations.

2d *Health sector staff urgently need training and support* in their work in order to become better informed, less judgmental and more supportive, especially of their female clients' diverse requirements (Khanna et al, 2002; Dhungana et al, 2002). For instance, they need to recognise the importance of *confidentiality* of all patients. Health staff also need support to think about their own HIV status, and assurances that they will not lose their jobs on potential discovery of their HIV diagnosis. HIV-positive women can be trained and *employed* as pre- and post-test counsellors, and as ARV peer educators.

2e *A radical overhaul of health policy is needed.* Recommendations 2a-2d above can only really take place in a sustainable way if the health service of each country is reviewed and restructured to ensure that it provides services that fully respect the equal rights of females as well as males, and where HIV-positive people as well as HIV-negative or untested people have good, non-judgmental gender-sensitive health service provision. This includes the need for health services to acknowledge that many of their own staff are also living with HIV or have a relative with HIV but are too scared to be tested or to tell others; such staff need full and unreserved support, since their personal as well as professional insights are especially valuable to their institutions.

Leadership needs to come from government as well as from senior medical staff across the region.

3. Support for contributions of HIV-positive people

3a *Positive women as speakers and advocates.* Since early in the epidemic, people have spoken out to put a face to AIDS and share the realities of living with HIV. Exposure to people living with HIV has a profound impact on people's attitudes to people living with HIV and to protective behaviour. Women in particular have been shown to make a significant change in young people's attitudes to HIV/AIDS (Paxton, 2002). If more HIV-positive people put a face to AIDS, human rights violations will reduce and community members will take on greater responsibility for caring for people with HIV and for protecting themselves from infection. Considering the plethora of motivated young widows, it is surprising that their skills have not been utilised to a much greater extent in the response to AIDS. Encouraging more women living with HIV to speak out takes time, commitment and support. Newly diagnosed women are far more likely to cope with their diagnosis and make an active contribution to the AIDS response, if they receive good, non-judgmental health care, early referral to peer support, help with disclosure to family members, and encouragement to maintain their self-esteem, especially in the face of others' criticism. They also need practical skills to advocate on their own behalf and to carry out public education.

Ideally, women who speak out should belong to an established network of HIV-positive people, who are able to give them the support they need on an on-going basis. External agencies can often fail to realise the burden on individuals of being asked to speak without adequate training and support. This can result in individual exhaustion and burnout (Manchester forthcoming) as well as feelings of tokenism.

3b *Involvement of positive women's organisations in decision-making.* The contributions of HIV-positive women and their organisations as true representatives in all aspects of decision-making that affects their lives should also be promoted in the Asia-Pacific Region. The 1982 UN Declaration of a Programme for Action and the 1994 "GIPA Principle" both uphold the rights to inclusion and strengthening of *organisations* of people with disabilities and with HIV, respectively, in all decision-making processes that affect our lives. But while the intention is there in these statements, their meaning is rarely fully realised. Few organisations recognise HIV-positive women's *organisations'* rights to involvement in their work and often assume either that an HIV-positive man can speak for all HIV-positive people, or that a few individual women can be expected, as tokens, to represent the views and perspectives of the vast number of women and girls across the region. This is unfair both on the individuals concerned and on the networks of positive women who have formed themselves across the region. *True* involvement should mean that the skills and experiences of *organisations* of HIV-positive women – including young women - could be harnessed at all stages of prevention, care and support work within the region. The HIV-positive women representing these organisations are already doing much – and could do much more if their own initiatives were properly funded. Moreover, they also have much more to offer in terms of their diverse skills, experience and insights, if they are given a proper place at the table. These networks often lack funds and are in need of capacity-building

with regards to fund-management, strategic planning and other administrative processes, in order to articulate their visions.

3c *Women's roles in HIV networks***.** The equitable role of HIV-positive women in organisations of HIV-positive people across the region and in individual countries also needs to be upheld. Many organisations of HIV-positive people receive funding from donors, but whilst most of the membership is female, the leadership positions are mainly held by men. Donors and the leaders of these organisations need to ensure that there is accountable leadership from women as well as men, in proportion to the membership of the organisation, and that the organisations concerned address programs of specific concern to the particular challenges facing women in the region.

3d *HIV-positive women's support groups.* HIV-positive women are excellent providers of self-help support, especially to women who have recently learnt about their status. Many positive women support one another, in terms of information sharing about living positively, prevention of further exposure to infection, and many other aspects of living with HIV, on a voluntary basis and often with very little funding. The contributions of these self-help groups are often overlooked and rarely adequately financed. They also need strong support through proper recognition, skills-training and office space.

4. Contributions of other civil society organisations and individual women and girls

4a *Other concerned groups of women* can make key contributions to reducing the discrimination faced by HIV-positive women. The work of the Indian Women Lawyers' Collective, for instance, is already raising awareness of the gulf between policy and practice. The contributions and expertise of other groups, such as the Sonagachi sex workers' cooperative in India, women's environmental groups, and other international women's movements should all be harnessed. These groups also need to find ways of making their own organisations safe spaces for their members who are HIV-positive, so that they can be encouraged to disclose their status to their fellow members and build ways of supporting one another, as well as forging or strengthening alliances with other relevant organisations.

4b *Many individual women and girls* in the region, whilst not necessarily themselves HIV-positive, or not yet aware of their status, are making direct, long-term, significant yet invisible contributions through caring for close family relatives. These carers often feel highly isolated and are also often badly discriminated against because they are related to people with HIV; yet their contributions, views and voices also need to be included, especially when issues of community or home-based care are discussed. Their needs should be supported financially.

5. Creating a supportive and enabling environment across society

HIV is increasingly a heterosexual pandemic in the Asia-Pacific region. Often older men take younger women as their wives; older women encourage their daughters into these marriages or are themselves older wives of men taking younger sexual partners. Traditional gender norms, whereby girls are trained not to stand up for their own wishes, but to serve and obey men and

accept their dominance in relationships, and whereby boys are brought up to adopt dominant roles in society *have* to change, in order to protect both women *and men* from this pandemic.

In order to protect young women from infection and from the discrimination which goes with it, both young women and men and older women and men need access to education and support programs which question and challenge these traditional gender norms. Thus *all* sections of society need to learn of the potential dangers inherent in unprotected sex and unequal gender relations. They need appropriate information and education about sexuality and about the fatal effects of unequal gender relations, together with the space to learn and practise skills in negotiation.

Moreover, communities need to have access to good programs that enable them to recognise the importance of giving community-wide care and support to people with HIV. Community-based care and support programs can have multiple benefits: they can increase everyone's awareness of their own personal vulnerabilities to the virus; they can enable positive men, women and children to feel more supported where it matters most; they can reduce the care burden on women by helping men to feel more ready to get involved in shared care and shared household expenditure; and, perhaps most importantly, by reducing the need for confidentiality at home around HIV, they can reduce heterosexual transmission from men to their wives, mother-to-child transmission through breastfeeding (which women often continue to do for fear of others guessing that they must be HIV-positive) and can also increase potential local access to drugs for opportunistic infections and to ARVs. Thus, more than ever, good community-based programs need to continue and expand, in order to create safe enabling home environments for everyone.

5a *Some pioneering NGOs are doing much to transform traditional gender-roles in the region and their efforts need greater recognition and financial support.* Community-based initiatives, which recognise the growing heterosexual dimension to this pandemic, and the need for better *communication* between men and women on all matters, are crucial. There are pioneering programs, such as the gender and social justice work of the Society for Integrated Development of Himalayas in India, which nurtures young men's partnerships with women (Gupta et al, 2004); the work of KHANA and partners in Cambodia, which challenges traditional gender roles with soldiers and others (Sellers et al, 2002); the adaptation and use of the "Stepping Stones" package on gender, HIV, communication and relationship skills with whole communities in southern India (Bhattacharjee, 2003). All these need scaling up or adaptation and duplication elsewhere. Moreover, there are many committed HIV-positive people – men and women alike - who would be ready and willing to be trained and *employed* as facilitators of such community programs. NGOs would do well to collaborate with them, in mutual sharing of their knowledge and skills.

5b *Schools-based opportunities are essential.* For boys and girls who are in school, the school authorities also have an important role to play, provided that boys and male teachers and other staff are also included in effective HIV-prevention programs. The curriculum, which should include information on the effects of gender violence on the whole family, can significantly and considerably reduce young women's likelihood of contracting HIV and of being shunned if they do. Good, non-judgmental sex education, delivered before people make their sexual debut,

results in later age of first intercourse, higher recorded rates of monogamy, and a greater incidence of condom use. Examples such as the YAAR project, working with young men in schools in Delhi to explore gender and sexuality issues, should be more widely disseminated. HIV-positive women (and men) are perfectly placed to carry out such education if appropriately trained, accredited and employed. Formal educators need to get girls back into schools, by creating flexible teaching times and respite care options for them, and get positive women (and men) talking with girls (and boys) about sex and HIV.

5c *Workplace and faith-based initiatives* also have a key role to play in HIV public education. Many senior business managers, as well as priests, imams, monks, nuns and other holy people are also HIV-positive. The more their institutions support them to disclose their own status and share their experiences with others, the more support can be fostered for junior staff (who are often women) or religious followers.

6 Summary: Multiple levels and multiple linkages

No one sector of society can create the changes that are needed to end the discrimination faced by HIV-positive women across the Asia-Pacific region. The AIDS pandemic has only just begun and creates a threat like no other to the stability of the whole region and the fabric of its many richly diverse societies. Different sectors of society can contribute to a shared vision of how the world might treat HIV-positive women and girls and their families and communities. These recommendations are not exhaustive and there are many groups not mentioned here, such as complementary therapy practitioners, media, military, police, artists, writers, who each also have a significant role to play. The response has to be at multiple levels - local through to global; it must be through multiple media – broadcast, writings, graphics, drama, poetry, dance and music; and must address multiple factors – legal, economic, social, physical, spiritual, psychological and sexual. AIDS challenges us to tackle the greatest taboos facing humanity – sex and death. The task before us is extraordinary – but then so are many of the groups of people who are facing it, creating innovative ways of thinking and working and, in the process, reshaping the world for the mutual benefit of all. The responsibility for the rest of society is to provide the support and resources they need.

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YAAR project: Contact person: Alok Srivastava
323/B, J&K Pocket, Dilshad Garden, Delhi-110 095 Phone: (91) (011) 2270071; e-mail: yaar@happysoul.net