



ICW VISION PAPER 4

HIV Positive Women and Human Rights



HIV Positive Women and Human Rights

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. However, HIV positive women and men and children are subject to degrading and discriminatory treatment, causing blame, despair, isolation, shame and leading to little or restricted freedom of choice or movement in all areas of life. Moreover, gender inequalities in all areas of life increase the abuse of sexual and reproductive rights, as well as legal, economic and political rights for millions of women worldwide. Women's unequal social, economic, and legal status is increased by a positive HIV status, and vice versa.

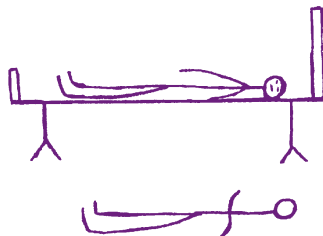
Violations of reproductive rights faced by HIV positive women include not being allowed the freedom to decide to have children or not to have children, or to decide on the number and spacing of children. Younger women with HIV, in particular, who do not already have children when they are diagnosed, often want to try for a family. However, they face pressure from health care providers not to have children and are not given sufficient information about reducing mother-to-child transmission. Women who do not want to have children can face pressure by family members to have a family, or be unable to negotiate contraceptive use with partners.

...the doctors also found out I was pregnant. I did not want to have a child at this stage and requested the pregnancy be terminated. The doctors only agreed to the termination on condition that I consented to sterilisation. I had no option. (Personal testimony, South African positive woman, 2003)

I once asked my husband - what would happen if I contracted HIV? He did not believe me. We have never used a condom and he said he wanted us to have a baby. (Thailand Voices and Choices, 2003)

HIV positive women are also often unable to decide freely on how to rear their children. For example if they or another family member becomes ill, they may have to withdraw children from school to help with chores in the home or income generation.

Violations of the sexual rights of women and girls to decide when, in what way and with whom we have sex, often leave us unable to protect ourselves from HIV or indeed to protect our health and well being once we have HIV. Marriage is often the only source of social and economic status and security for women. Even though rape in marriage is often illegal, many women and men still believe that sex on demand within marriage is a man's right. Women who refuse sex or try to negotiate condom use are frequently accused of being unfaithful, are physically beaten or 'punished' in some other way



When we are tired and refuse to have sex with our husbands we are asked to sleep on the floor. (Smith and Howson 2002)

The global violation of the right to a secure economic livelihood hinders the response and increases the negative impact of the epidemic



What are Human rights?

Human rights are universal legal entitlements protecting individuals and groups against actions (or the lack of actions) that affect their freedoms and human dignity.

Human rights principles:

- Indivisible and inter-dependant – we can not have only part of a right, and to fulfil one right, we need to be able to fulfil others.
- Universal – human rights belong to all human beings, without discrimination regardless of gender, HIV status, race, religion, sexuality, age, ability and class.
- Inalienable – no one can take our rights away from us. We may not be able to fulfil all our rights, but they are ours nonetheless.
- Accountability – states and people are responsible for rights. We have responsibility in terms of each other in terms of rights, and states have responsibilities to make sure that rights are fulfilled.
- Participation – to fulfill our rights we all need to recognise our responsibilities, and the roles we must play to fulfill them.
- Internationally agreed and legally protected – there are international and national bodies whose job it is to monitor whether rights are being violated in any particular country or context.
- Beyond state sovereignty – no state can disregard the need to work towards enabling its citizens to fulfill their rights. Any state which does so runs the risk of international sanction.

(ICW 2004a)

A recent UN Commission on Human Rights resolutions have stated that the term “or other” in non-discrimination provisions in international human rights texts should be interpreted to cover health status, including HIV/AIDS. The commission has also confirmed that ‘discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards’. This means that, even when HIV hasn’t specifically been mentioned, if it says ‘other status’ it is illegal for anyone to discriminate against us on the basis of our HIV positive status.

The right to non-discrimination is enshrined in Article 2 of the Universal Declaration on Human Rights (UDHR); International Covenant on Civil and Political Rights (ICCPR); International Covenant on Economic Social and Cultural Rights (ICESCR); Convention on Elimination of All Forms of Discrimination Against Women (CEDAW); Convention on the Rights of the Child (CRC); the African Charter.



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 participant, Voces Positivas, ICW 2004b)

Women's generally less secure status in the workplace can leave us with little choice but to secure livelihoods through exchanging resources for sex, so possibly sacrificing long-term health for short-term subsistence. This is true for HIV positive and HIV negative women. When women and girls need to exchange sex for resources or to ensure the 'smooth' running of our livelihoods we are unlikely to have the power to negotiate safe sex. Moreover, women who are involved in sex work generally face greater discrimination than other women do - despite the fact that for some, sex work provides a more viable livelihood than other alternatives, or that in some situations sex workers practice safer sex.

Yes, it happened to me. My friends at the flat gossiped about me. They knew that I was HIV infected from my work [sex worker]. They said that I've got AIDS and asked other people not to come close to me, and not to let me touch their children. (Thailand Voices and Choices)

We're workers, this is our work, this is what we do and we usually take extremely good care to be safe. It's often the man who attempts to bully a sex worker into not using a condom. (Thai interviewee, ICW 2001)

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Due to stigma and HIV/AIDS-related discrimination, the rights of women living with HIV/AIDS are violated, simply because they are known, or presumed, to have HIV/AIDS.

My dream, what I was – a nurse known by all, with prestige, loved by everyone – had gone. I fell into a depression and forgot everyone in the world. (Participant from Mexico in Voces Positivas)

The fear of such discrimination discourages women from disclosing their status or seeking testing or treatment.

In some regions violations of women's property rights are not only an affront to human rights, they also limit the effectiveness of the fight against HIV/AIDS. When HIV positive women's property rights are violated we are less able to care for our well being and the well being of our families. Judith, a 27-year-old widow from Kenya, was infected by her husband. Her husband was tested in 1996 and only revealed his status two days before he died in 2001. When she revealed her status to her brother-in law she was chased away from her home. Her door was broken so that she could not return to my home and her children. However the Federation of Women Lawyers in Kenya helped her reclaim her home:

With the encouragement from FIDA I learnt about my rights and went back, reported the case and I won. But the brother in-law insisted that he inherit me." (ICW 2004a)

In many African countries, women are excluded from inheriting, evicted from land and homes by in-laws, stripped of possessions, or subject to widow inheritance in order to retain access to their property.

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HIV positive women who are already socially marginalised tend to face greater violations of our rights. Women in prisons, sex workers, and women who use drugs, for example, are often subject to discrimination and denied care and support. Beverly is living with HIV and currently at California Correctional Facility for Women at Chowchilla (CCWF), USA. [aidsinfonyc 2000]

I have a very hard time trying to understand why a facility this large would be unable or unwilling to properly care for and monitor HIV/AIDS prisoners. I am an activist for my sisters behind these walls, who are in need of better medical care. I have a wealth of information concerning AIDS. I am unable to fight CCWF's medical department ALONE! My days end with discouragement and defeat. I will not stop trying to give support and information.

At the age of 18 I started injecting opiates. Drugs and alcohol helped me to change my reality. [...] I drifted into theft to support my addiction. [...] In prison I had another test. This time it was positive. After I was released, the head of police told me that if he saw me in town he would kill me. (Ukrainian interviewee, ICW 2000)

HIV positive women are also denied access to a range of other rights, which include access to good non-judgmental health care and voluntary counselling and testing. ICW research, for example, reveals that women often have little choice over whether to be tested and are given little information about the nature of an HIV test or test results.

When I was pregnant and went for the ante-natal care, I was told to have a blood test. They did not explain at all what kind of test they were doing. (Thailand Voices and Choices)

Many countries have signed up to international agreements that seek to protect women's rights, such as United Nations General Assembly Special Session on HIV/AIDS (UNGASS), the Cairo International Conference on Population and Development (ICDP), and the Beijing Platform for Action. However they often seem miles away from the reality of most women's everyday lives. Many women with HIV do not know that we have rights, what these rights are and how to go about gaining them.

How can we advocate for our rights if we also face violations of our political rights and our right to participate at all levels of institutions that make decisions that affect our lives and the lives of our families? It is true that to fulfil one right, we need to be able to fulfil others. We can not exert our sexual and reproductive rights if our economic, legal and political rights are violated.

We now call for the rights outlined on the front page of this leaflet to be *transformed* into action.

ICW Call for Action

From the start, HIV positive women have emphasised the HIV and gender connection in international debates. We may still be fighting to ensure a place for HIV positive women in the inner circles that determine HIV/AIDS policies, but HIV positive women have helped to ensure that international human rights instruments recognise and respect women's sexual and reproductive rights. We have insisted that tackling gender inequality is integral to the fight against HIV/AIDS.



We call for:

A human rights framework:

- Promote a human rights framework which provides access to existing procedural, institutional and other monitoring mechanisms for enforcing the rights of women and people living with HIV and AIDS, and for confronting and amending discriminatory action.

Collaborations:

- Develop collaborations between advocates groups, women's rights and liberation groups, HIV/AIDS organisations and the media in recognising, defining, calling for and monitoring the respect of human rights.

Women's rights and self-help groups:

- Support women's groups that challenge discriminatory traditions and customs based on gender stereotypes and the belief that women are inferior.
- Develop and support accessible legal support and advice services – these are often provided by women's rights groups.
- Support self-help groups – as they often form the basis for a shared understanding of rights, as well as offering a source of collective strength for advocacy on human rights and gender equality.

Policy making and participation:

- Promote the participation of HIV positive women in discussions around and formulations of rights, as well as in development of policies promoting their implementation.
- Promote accountability among decision makers including community and religious leaders – they all need to advocate for inclusiveness and equality irrespective of HIV status and gender
- Respect the contribution and participation of HIV positive women, including HIV positive young women, in all decision-making processes related to our lives.

Working towards recognition and a respect for rights

Exploring rights:

Positive Women: Voices & Choices (Zimbabwe, Thailand, Francophone Africa) Voices and Choices is a project led by positive women to explore the impact of HIV on their sexual well being and reproductive rights, and to promote improvements in policy and practice. ICW has been working with national networks and organisations in these countries, including the Women and Support Network in Zimbabwe, Power-of-Life and Mahidol University in Thailand, and REVS+ in Burkina Faso. Information can be found on the ICW website.

Developing a supportive environment for claiming rights:

REVS+ (Reseau Espoir, Vie, Solidarite – the Hope, Life and Solidarity Network) is an association of HIV positive people. REVS+'s aims are to strive for a better life and build projects for the future. REVS+ provides information on HIV and treatment issues, helps with school fees of orphans, gives information and support about essential generic medication and ARV treatments, provides nutritional support, creates income generating activities, offers pre-test counselling and provides a medico-social presence in public health services. (ICW 2003)

I decided I wanted to be an activist and fight for the rights of women who are positive, like me...I decided to join the Association [REVS+] because I had seen women on TV openly talking about HIV. Me too, I did a testimony. (Participant of Burkina Faso workshop 2003)

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The Positive Women Network (PWN), a self-help initiative of women living with HIV and Aids in India provides counselling, monthly support group meetings and training programmes. PWN also works with the Indian government, non-governmental organisations, care centres and international bodies to promote the rights of HIV positive women.

PWN is fighting for a better life for the women and children living with HIV in India. A life not secluded; a life free from stigma with all our rights intact. (President of PWN)

Claiming rights:

Federation of Women Lawyers, Kenya (FIDA) Realising that women face major systemic obstacles that prevent them from full enjoyment of their rights and privileges, FIDA Kenya:

- offers quality legal services to a limited number of women
- creates awareness of legal rights and educates women on how to claim them through self representation in court
- researches, monitors and reports women's rights violations
- lobbies and advocates for reform of laws and policies that discriminate against women and
- undertakes public interest litigation.

(Source: www.fidakenya.org)

I told him why I refused to be inherited because I did not want to infect someone and I did not want to be reinfected. So by the support of the government and the Federation of Women's Lawyers, I managed to stay in my house and I know I will inherit my husband's portion of land. (HIV positive participant of Kampala Conference 2003¹)

Changing legislation:

HIV positive women in Nicaragua and the Dominican Republic have taken legal action against their respective governments in order to achieve universal access to treatment for all people living with HIV/AIDS. Some of the on-going work of HIV positive women that took part in ICW's Voces Positivas – a process of empowerment and training for HIV positive women from Central America and the Caribbean, 2003 – is discussed further in the ICW newsletter, issue 25 (ICW 2004b).

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¹ 11th International Conference of HIV Positive People, Kampala, Uganda, October 2003.



ICW Vision Papers (2004) have been written for HIV positive members and our supporters to use when advocating and organising around ICW's visions, aims, and objectives. In them you will learn what ICW's positions are and be able to represent ICW well at any meetings or in any groups you attend, or if you are asked in any circumstances to explain what ICW stands for. They are meant as an aid to your own work and can be used creatively. ICW welcomes your feedback and evaluation of its vision papers. Please tell us how you have been able to use them. We'd love to hear from you.

This Vision Paper on Human Rights is one of five ICW Vision Papers. This series outlines ICW's position on: access to care and treatment; participation in policy-making, gender equity and poverty; human rights; and HIV positive young women. They are available in English, Spanish and French.

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The International Community of Women Living with HIV/AIDS (ICW), a registered UK charity, is the only international network run for and by HIV positive women. ICW was founded in response to the desperate lack of support, information and services available to women living with HIV worldwide and the need for these women to have influence and input on policy development.

All HIV positive women can join ICW for free. Just contact us at:

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