



ICW VISION PAPER 2

Access to Care, Treatment and Support (ACTS)



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Every year, HIV/AIDS causes the death of an increasing number of women. In 2002 over 1 million women around the world died of AIDS (UNAIDS 2002). Access to anti-retroviral treatment (ART) could reduce this figure drastically. Some of us experience side effects from these powerful drugs, but there is no doubt that, so far, ART has turned HIV into a much more manageable chronic condition which may no longer be a death sentence. However, ICW is keen to point out that treatment is not just about providing ART; care, support and other medications are also needed for all HIV positive people.

ICW's vision therefore is *universal* access to care, support, and treatment for everyone with HIV, regardless of their gender, age or lifestyle. Currently, few HIV positive people have access to treatment. The World Health Organisation (WHO) is committed to getting three million people living with HIV on ART by the end of 2005 (under the 3 by 5 Initiative). There is, however, considerable evidence to show that women and girls face challenges in gaining access to treatment for any health condition. Given the stigma surrounding HIV, it is likely that access to HIV drugs will be even more challenging for women and girls.

The **Global Coalition on Women and AIDS** is a new UNAIDS initiative made up of activists, government representatives, and community workers. Its efforts will focus on preventing new HIV infections among women and girls, promoting equal access to HIV care and treatment, accelerating microbicides research, protecting women's property and inheritance rights and reducing violence against women. ICW is leading the Global Coalition's work on women's and girls' access to care and treatment. The Global Coalition on Women and AIDS wants to ensure that half of the 3 million people are women and girls. ICW believes this will only be possible if HIV positive women, our networks and support groups are involved in all initiatives.
(www.womenandaids.unaids.org)

ICW firmly believes that HIV positive women and girls are best placed to understand the barriers we face in accessing care and treatment. We are also the best people to develop, design and deliver better ways of making treatment available to HIV positive women and girls around the world. This should include making sure that HIV positive women and girls are trained and employed to act as treatment advocates or treatment distributors. Without this, we believe the barriers which prevent women and girls accessing treatment will not be adequately addressed, and HIV positive women and girls will continue to miss out on treatment.



So what do we see as the main barriers to women's access to treatment?

Cost

Some countries offer universal access to ART. However, cost affects uptake. Where ART is free, more women take it up. Where there are costs involved, fewer women access it. Many countries lack the political commitment or the ability to ensure that barriers to treatment access are overcome. Moreover, for some countries it is economically impossible to guarantee universal access to ART. Particularly as universal access involves ensuring that systems are in place to distribute drugs, that guidance is provided about drugs and care regimes, and that care and support is given to HIV positive people who face problems with ART. Even when treatment is provided free of charge, there are often other costs involved – the cost of transport to the clinic, or the time lost from work and caring duties.

There's a lot of bureaucracy within the system in Panama and it's difficult to obtain the treatments. If we are on social security and insured, the process takes far too long. If we rely on the Ministry of Health for antiretroviral treatment (which has only been possible for the past year) it is all centralised in the capital. Living in the provinces means that once a month, we have to make a four to six hour trip in order to reach the capital in order to obtain treatment or the special CD4 and viral load tests. (Panamanian participant, Voces Positivas, ICW 2004).

About the anti-viral drug, it is good to have it but one has to take it for a lifetime. It is very expensive, and we have no money. (Thailand Voices and Choices, 2003)

Cost and distance barriers are likely to be more severe restrictions for women than for men. Women often lack money, or the time to travel long distances to distribution points, and often have to account for their time to husbands or other family members.

The limitations of health centres as distribution points

The main strategy of 3 by 5 aims to provide access to treatment for women by channeling drugs through antenatal and health clinics. ICW's concern is that this strategy will mean that women and girls who are not pregnant will not be reached. Girls are often not eligible for treatment for HIV or sexual health problems at health centres because of age restrictions (or because they do not have someone to speak on their behalf).

Health services often fail to provide appropriate treatment, psycho-social care and support. Too often, health personnel dishonour and discriminate against HIV positive people. They may have fears about their own status or lack correct information about HIV. Whatever the reason, judgmental attitudes about HIV positive women's 'right' to services, including treatment, abound. The belief that an HIV diagnosis is a death sentence and that those living with HIV are beyond hope, affect women's ability and confidence to access treatment.



If women are treated badly they will not want to return to the clinics.

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 did not 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 IUD. (Thailand Voices and Choices)

If women are treated badly they will not want to return to the clinics. 3 by 5 also has to take into account that without care and support, treatment and morale will be hard to maintain.

Lack of research on women and ART

ICW is also concerned that although ART has had a positive impact on many women's lives, resistance to ART for a growing number of people has limited their treatment options. Treatment options are also restricted for people living with HIV and hepatitis C co-infection. ART side effects can be severe and are often disfiguring.

Medical practitioners lack knowledge of how HIV and opportunistic infections impact on our bodies, and do not know enough about how ART or other technologies such as microbicides may affect our bodies. There has been very little research so far on whether resistance and side effects are different for women and men. Women's experience suggests that physiological

responses during pregnancy and breastfeeding may cause drugs to work differently than at other times – and that hormonal differences between women and men may mean drugs have a different impact on us.

ICW members are also concerned that there is not enough research on these areas in relation to young women, including how ART affects young women's fertility (Young Women's Dialogue, 2004).

Lack of research, screening and treatment for opportunistic infections

ICW is concerned that HIV advocates often fail to highlight the need for treatment initiatives to include screening and treatment for opportunistic infections and HIV-related conditions such as cervical cancer.

Gendered support, care and treatment plans

Stigma and discrimination around HIV within communities, families and health services can prevent HIV positive people, particularly HIV positive women, accessing services and being more open about their status. HIV positive women are often subject to discrimination and stigma because of social values surrounding the importance of female purity and virginity and this affects meaningful access to a range of information, treatments and support. Stigma and discrimination is made worse when there is little community education and awareness about HIV and where health service personnel do not respect a patient's right to confidentiality.

In Gabon, you have to have medical tests before marriage. If one partner is found to be positive, then the results are made public to the prospective in-laws and the whole Christian community. (Voices and Choices Francophone Africa, 2003)



HIV positive women and girls often require different treatment and care plans from men. The psychological pressures women face are often very different to those of men, and are often linked to women's and girls' traditional roles as unpaid carers within the household and community.

A further barrier to accessing treatment and other health services is gender inequality within families. Many women involved in ICW research had to obtain permission from a husband or a relative in order to seek care. This is particularly difficult when women have to ask for money, or take time away from household chores, and more so when we have not disclosed our HIV status to family members. ICW is also concerned that ART provided to women may be used by male relatives or that male partners / relatives may be prioritised for treatment if the household only has enough money to afford one lot of treatment.

Workplace discrimination

Businesses, faith-based organisations, community groups, development organisations, and governments have taken important strides in recognising that many of their colleagues live with HIV. However, there is often an 'us' and 'them' mentality that sees those at risk as 'others'. This leads to a lack of understanding of everyone's risk and of how we are all affected on a daily basis by HIV. It also leads to a reluctance to be seen to be taking medication.

Thus access to treatment does not mean simply going to the shop and purchasing a few pills. It is a lifetime commitment that requires an ongoing supportive environment and networks of care and support. This is difficult to achieve when funders focus on short-term projects and when communities are immersed in stigma and discrimination about HIV and AIDS.

ICW Call for Action

UNAIDS has asked ICW to act as the convening agency for the treatment and care arm of The Global Coalition on Women and AIDS. This means we will encourage thinking and action on access to care, treatment, and support for all HIV positive women and girls.

We call for the following:

Gendered and generation-specific research

- Different treatment and care regimes call for the development of proper gender-equitable and age-related research trials, both on drugs and on other aspects of care and treatment.
- Microbicides, vaccination and contraceptive research also have particular gendered dimensions that need to be considered, as well as the different impacts they have on the bodies of HIV positive women compared to HIV negative women.
- More research into opportunistic infections specific to women and HIV-related conditions such as cervical cancer, as well as more research into screening and treatment options for these.

Equitable access

- Understand the challenges facing women and girls in gaining access to treatment of any kind. HIV positive women are best placed to develop appropriate solutions, and should be involved and employed to help develop access to treatment programmes.

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- Ensure that when ART and other HIV-related treatments are made available they are accessible to HIV positive women, by making the drugs mobile, and ensuring a wide range of distribution points in addition to health services. This should include training and employment of HIV positive women and positive women's organisations as treatment promoters and ART distributors.
- Provide accessible screening and treatment for opportunistic infections and other HIV-related conditions, as part of the treatment package for HIV positive women and girls.

Participation

- Consultation with HIV positive people and others who work directly with community members and other relevant groups, in creating 'services to fit people' rather than 'people to fit services'.
- Training and employment of HIV positive women and girls to develop information about access to care, treatment and support.
- Training and employment of HIV positive women and girls to develop treatment access programmes which are appropriate and will guarantee accessibility to women.

Care and support – not just drugs

- Develop on-going programmes which promote care, support and respect for HIV positive people within our own communities and within the health services.
- Give communities the support and training needed to create neighbourhood environments which ensure compassion, empathy and understanding.
- Support holistic health approaches which promote good nutrition and deal with psycho-social issues.
- Support programmes which recognise women's roles as care givers and the immense chronic and traumatic impact of so many deaths on everyone's lives

Treatment is a lifetime commitment that requires an ongoing supportive environment and networks of care and support.

Workplace policies

- Encourage the involvement of HIV positive people in workplace policy development and implementation, which promotes the retention and employment of HIV positive staff, including women, and which ensures that benefits to staff include a range of appropriate care and support, which is not just drug specific.
- Promote a proactive awareness of the way in which HIV can affect all our lives throughout the whole management and staff body, from top to bottom.

Examples of work on care, treatment and support

Advocating for access to ART

People living with HIV and AIDS including HIV positive women have advocated for universal access to ART. For example, 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 and AIDS (ICW 2004).



Providing care and support

Many organisations have been involved in the provision of care and support. For example:

The Kenyan-based group Women Fighting AIDS in Kenya (WOFAK) supports a number of care givers who make home and hospital visits to people living with HIV/AIDS. The care givers provide nursing care, nutritional support, and counselling as well as community education for family and community members.

The doctors and nurses behaved as if they were tired of me... If my friend from WOFAK did not come, I think I would have died by now. She washed me and ensured my bed linens were changed. It is hard for them to visit me everyday but the days they come, I felt a lot of relief. It is very encouraging to be visited in the wards. (Woman from Kenya)

Hilda Esquivel ICW member from Mexico describes the work of the project – Empowerment of Women. *I started looking for women in 1999 when people still believed there weren't many infected women. I started to work in a project called Empowerment of Women and explored ways to build women's skills, giving tips on looking after yourself, how to find nutrition specialists, gynaecologists, dermatologists and all the services related to HIV. I've never let go since then. It has been a question of renewing, changing strategies and planning. The women's ages range from between 15 and 45. Many of them lack information or have the wrong idea on issues such as prevention. Our culture makes it difficult to rescue women. They do what the husband or partner says. They are not autonomous. If he says no, then it is no. That's another good reason to empower them, so they can make their own decisions regarding themselves and their families.*

In Costa Rica, Nicaragua, Guatemala, and El Salvador positive women have obtained space in referral hospitals where they can meet other positive women and provide support and information. Positive women in these countries have also trained health personnel on the specific needs of positive women (ICW 2004).

Challenging stigma and discrimination in health services

Team leaders for ICW research on women and HIV in Zimbabwe organised community workshops on the same theme. They felt that nurses who had attended really changed their negative attitudes towards HIV positive women. Health care workers who attended the Zimbabwe Voices and Choices national advocacy workshop in November 1999, in Harare, also took women's criticisms on board and recognised their responsibility in addressing community stigma and discrimination towards women with HIV (ICW 2002).



References

ICW, 2004, *ICW News Issue 25*, London: International Community of Women Living with HIV/AIDS (ICW)

ICW, 2002, *Positive Women: Voices and Choices*, London: International Community of Women Living with HIV/AIDS (ICW)

UNAIDS, 2002, *AIDS Epidemic Update 2002*, Geneva: UNAIDS

ICW research programmes and workshops mentioned in this Vision Paper

Young Women's Dialogue, Southern and East Africa, Durban, 19-23 April 2004.

Voices & Choices Zimbabwe and Voices, 2002, and Voices and Choices Thailand, 2003

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 practise.

Positive Women: Voices and Choices Francophone Africa: Workshop On Sexual And Reproductive Rights And Experiences Of Women Living With HIV/AIDS, Bobo Dioulasso, Burkina Faso, September 1 to 7, 2003.

Voces Positivas – process of empowerment and training for HIV positive women from Central America and the Caribbean, 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 access to care, treatment and support 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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