



ICW VISION PAPER 1

HIV Positive Young Women



HIV Positive Young Women

In most parts of the world, young women are more vulnerable than young men to HIV and AIDS. Most new infections of HIV occur in young women between the ages of 15-24 (UNAIDS 2003). This is due to biological, social, cultural and economic reasons. Moreover, the consequences of living with the virus can differ dramatically for young women and men, boys and girls. Despite this, the concerns of HIV positive young women and girls are often absent from HIV advocacy agendas and sidelined in research, and HIV positive women, old and young, are often excluded from debates about treatment and prevention. Our absence from forums where decisions about HIV/AIDS are made means that the skills, insights and experiences that young positive women have to offer are ignored. These issues need to be addressed urgently.

Developing a common agenda

A group of young HIV positive women from across Eastern and Southern Africa met in Durban in April 2004. They came together for a unique dialogue organised by the International Community of Women Living with HIV/AIDS (ICW) in partnership with Youth Against AIDS Network (YAAN) and Gender AIDS Forum (GAF). Their dialogue and conclusions, along with input from other young HIV positive women around the world, form the basis of this paper.



Young women members of ICW have identified the following as key priorities:

1. Young women living with HIV and AIDS are unable to access their sexual and reproductive rights

ICW believes that ABC¹ does not recognise women's sexual and reproductive rights and does not provide workable options for women, and even less for young women. Our research shows that social, economic and cultural pressures mean that young women, and particularly young HIV positive women, are all too often unable to exercise these rights.

The Young Women's Dialogue defined a goal: that all young women living with HIV and AIDS have access to their sexual and reproductive rights, and are supported in exercising these rights. Six fundamental sexual and reproductive health rights have been prioritised by young HIV positive women within ICW.

The right to sexuality education in and out of school



Kousalya, ICW's South Asia Trustee has been living with HIV for nine years. She contracted HIV when she married at twenty, and her words illustrate the importance of sexuality education in enabling young

women to exercise our human rights. *I was not informed about HIV/AIDS or reproductive health issues until when I got married and got infected by my husband during my first sexual intercourse. In India it is very difficult for young women and girls to talk about sex or to even negotiate for safer sex. Currently in India young women have no access to information.*

¹ Abstinence, Be faithful, use Condoms (ABC) – favoured by the Bush administration, it currently is the lead approach of many international agencies working on HIV.



The high social value placed on virginity in unmarried young women and girls often puts pressure on parents and the community to ensure they are kept ignorant about sexual matters.

No one in the church spoke to me about sex or sexuality and all the problems that these issues raise. (HIV positive woman from Bolivia, 2003)

The importance of 'innocence' prevents young women, including HIV positive young women, from seeking information about sex or services relating to our sexual and reproductive health or rights, including information about sex as an HIV positive young woman.

The right to reproduce and have children, including safe conception, safe pregnancy and safe outcomes of pregnancy

Young HIV positive women often face judgmental attitudes from health workers who believe we should not have children. ICW believes that HIV positive young women should be supported to make our own decisions, with access to good information about safe conception and pregnancy.

When my husband and I decided to have a baby we discussed everything. The doctors wanted to give us some counselling but I told them we already knew the issues and it was up to us. I knew they would try to discourage me and give us the negative side of having a child. I knew if she was HIV positive we would love her until she died. We understood all the possible consequences. I can say I'm very lucky because we have a beautiful HIV negative baby born to two positive parents. (ICW member, Philippines, ICW 2001)

Young HIV positive women also need clear information after pregnancy and support in deciding whether or not to breastfeed.

The right to safe termination of pregnancy, and the right not to be forced into termination of pregnancy or sterilisation

HIV positive women the world over face pressures to terminate, not to terminate, and to be sterilised – and often find ourselves trapped between the expectations of medical workers and those of our partners and families.

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 young woman, 2003)

When I lived with him, I got pregnant. I decided on my own to have the abortion and get sterilised at the same time at a hospital. I did that because I had the infection. (Thailand Voices and Choices, 2003)

This is my first pregnancy. I would really love to have a child. (Zimbabwe Voices and Choices, 2002)

Young HIV positive women face particularly difficult choices, whether the pregnancy is wanted or not, and often find ourselves dealing with twin prejudices against young pregnant women and HIV positive women.

The right to protected sex

Worldwide, women generally have little say over who we have sex with and when. Those of us who are able to choose whether or not to have sex with a male partner are nevertheless often unable to ensure condom use.



The reality is that much as we may want to practice safer sex, we may not be in a position to do so. Although we were both receiving counselling and information about the necessity to practise safer sex in order not to re-infect each other, he forced me into unprotected sex because I was his wife and he paid lobola for me. (Personal testimony, South African positive young woman, 2003)

Many health programmes fall short of helping young girls, both positive and negative, to acquire the knowledge, negotiation skills and assertive behaviours we need to navigate the transition to adulthood, the practice of safer sex, pleasurable sex, or the ability to say no to sex, if that is what we want.

I have a problem because my partner does not like using condoms. That is my battle every day. It will take time to adapt. (Francophone Africa Voices and Choices, 2003)

The right to sexual pleasure

Women do not stop being sexual beings because of an HIV diagnosis. Young HIV positive women have a right to sexual pleasure.

60% of new infections occur among young women and girls aged 15-24.

Wanted sex, good sex and right to enjoy sex is not something that is covered in many intervention programmes. All I can say is that sexual reproductive health activities concentrate on ABC and family planning, in other words, more of the shock tactics type of education. How do we expect young women to understand the importance of consensual sex and negotiating skills if education is only limited to prevention of pregnancy, STIs, and sex being a no go area in many societies? (Namibian participant, Young Women's Dialogue)

This is a right which is all too often denied to all women, whatever our age or HIV status.

Among the Fulani people of Guinea Conakry, women are not able to negotiate with men when it comes to sex. People believe that if a woman has sexual pleasure, it is because she has experience from other relationships, outside marriage. The fidelity of a woman is then questioned if she gets too much pleasure from sex. So the situation just continues: women cannot afford to be seen to enjoy sex too much. (Francophone Africa Voices and Choices)

The right to choose our sexual partners

Young women often lack the opportunity to choose our sexual partners – or to choose to abstain from sex. Men's place in society puts them in control, leaving women little choice. Rape, arranged marriage, and practices such as widow inheritance increase women's lack of ability to choose our partners.

Judith, a young HIV positive widow from Kenya, has chosen to abstain from sex since her diagnosis. However, this choice is one that many women are unable – or unwilling – to make, particularly where women are under pressure to form new partnerships for cultural, social or economic reasons.

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In our culture if a man dies, the wife should be inherited. If you are inherited, you cannot use a condom – it is skin to skin. (Kampala conference participant, 2003²)

Rape is a brutal denial of this right, whether within marriage or outside it. Gender violence also denies women our sexual rights. Both have terrible consequences for women, and these are often even more severe for HIV positive women.

Some women decide not to have sex but face abuse instead. They may even be raped and blamed. One young woman living with HIV I know did not want to have sex and was raped by a man. He did not know her HIV status. After discovering her status, her family and that of the rapist blamed her for transmitting HIV to the rapist. (Personal testimony, South African positive woman, 2003)

While some women may choose sex work as a way of securing their livelihoods, for others, particularly young positive women, there is no choice. Elizabeth's parents died leaving her with siblings to look after. Elizabeth's story reminds us that orphans who require support are not just young children:

There was no other way to find money. I started to have sex with anyone who would give me money. I knew all about AIDS [...] I had no choice. I had to feed the family and that time I was 18 years old. (Zimbabwe Voices and Choices)

2. Young women living with HIV and AIDS are unable to access ARVs and appropriate screening, prevention and treatment for opportunistic infections

The Young Women's Dialogue stressed the fact that we often have little information about our own health in general, and HIV and AIDS in particular. Often even the most basic information is lacking, such as the need for regular cervical smear tests (pap smears), the need for safer sex to prevent reinfection, whether or not to breastfeed, and the importance of early treatment of opportunistic infections.

It is often especially difficult for young positive women to access health and HIV/AIDS services. We may fear the judgmental attitudes of health workers, or lack the time, money and independence to get to clinics, or we may have other responsibilities such as care responsibilities for other family members, which prevent us from getting to clinics. Young women may also be concerned that confidentiality will not be respected and parents or other family members will find out.

I haven't told my parents yet, but some of my friends know. I don't want to visit the local AIDS clinic in case my parents find out. I believe the news would be too shocking for them. (HIV positive young woman from Russia, ICW 2000)

Treatment access programmes fail to take the specific needs of young women into account. Medical staff are often ignorant of the needs of HIV positive young women, and there is a lack of research on all issues related to HIV positive young women. Much more research is needed, including research on the effect of HIV on young women's bodies; the impact and side-effects of ARVs on young women's bodies, particularly in relation to fertility; and opportunistic infections most common in young women and appropriate treatment for them.

² 11th International Conference of HIV Positive People, Kampala, Uganda, October 2003.



Clinical trials must involve young HIV positive women in ethical, gendered research if young women are to fully benefit from treatment access programmes.

3. Meaningful and active participation of young women living with HIV and AIDS

The Greater Involvement of People Living with HIV/AIDS (GIPA) principle provides only a starting point: involvement is not enough. GIPA does not specifically acknowledge the role of women, and even less so the role of young women, who are often less empowered and more disadvantaged. ICW believes that HIV positive young women's voices must be heard, and that this must be seen to be an integral part of any solution. In many parts of the world, young women are not allowed to voice their opinions. Communities and governments often do not support young women's initiatives, and we are seldom represented at national and regional levels.

The 'voicelessness' of women in general, and young women in particular, occurs in all sectors of society – in the home, in hospitals and health centres, in the workplace, and within religious organisations, communities and government. It is also evident within AIDS organisations and civil society groups.

The Young Women's Dialogue participants underlined the fact that:

In general, young women living with HIV and AIDS are not organised and do not have the skills to address their issues. Networking is not happening – space needs to be provided for young women. Organisations will not put issues of young women living with HIV and AIDS on the agenda without young women pushing them to do so. (Young Women's Dialogue).

ICW Call for Action

ICW advocates for the greater involvement of young women and girls living with HIV and AIDS at all decision and policy-making levels. We need to be involved in programmes that directly affect us, for example, programmes on access to care, treatment and support. This involvement is crucial for the success of any programmes meant for young women.

We call for:

Education:

- Continued access to education for HIV positive girls, for example, flexible learning times for those learning a living or helping at home during normal school hours.
- Systems to be put in place to ensure that HIV positive girls (and boys) are not discriminated against in schools.

Developing relationship skills:

- Non-judgmental skills-based training on relationships, sex, sexuality, and sexual identity, as well as communication and assertiveness training, and negotiation skills.
- Non-judgmental, thorough discussions with young women in sex education classes, to include the levels of risk or safety of a range of sex practices.

Health care:

- Access to good, non-judgmental, youth-friendly health care and support services and treatment for HIV, opportunistic infections and sexually transmitted infections (STIs).
- Access to sexual and reproductive health services for HIV positive young women, including birth control, and access to information on safe pregnancy, breastfeeding and abortion.

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Livelihoods:

- Programmes to develop livelihoods should always include young women and take into account the specific barriers we face in securing safe livelihoods, and owning and inheriting property.

Community programmes and education:

- Good, sustainable community-based programmes, which ensure that adult men and women and boys *all* respect the needs and rights of *all* young women and girls, especially HIV positive women and girls in their community.
- Appropriate cultural and educational work to challenge the view of HIV positive girls as victims, and to value our contributions and knowledge.

Involvement in programmes and decision-making:

- Involvement of young women and girls, and particularly young HIV positive women and girls, in decision and policy making, ensuring that we have a say in what happens to us in our communities and beyond.
- Help to develop the skills of young women to further respond to the AIDS pandemic.

Support groups:

- Young women may feel intimidated in HIV positive women's support groups and therefore may wish to set up separate groups, with support from others.

Human rights:

- Strengthen the identification and understanding of all the human rights of women and children, regardless of religion, class, and sexual orientation, in the context of HIV/AIDS.
- Promote the parenting rights of HIV positive young women, our rights to choose the custodians and guardians of we children when we die, our rights to write a will and decide on the management of assets on behalf of our children.

Research:

- Greater research into the effects of the HIV virus, and ARVs on the bodies of HIV positive young women as well as the development of female-controlled safer sex methods such as microbicides for HIV positive young women.

Examples of work involving young people

Recognising inter-generational pressure on young women:

Stepping Stones, a training programme on communication and relationship skills for all community members, recognises the inter-generational pressures on women and men to conform to particular behaviours that negatively affect their well being. Concerns specific to women, men, young women, and young men are discussed in age and gender specific focus groups and then each group considers the concerns of the others groups. (www.steppingstonesfeedback.org)

Working in schools:

Choose Life is a programme conducted in urban schools in Zimbabwe. It shares information on statistics, who is at risk, how HIV causes AIDS, myths and misconceptions, counselling and testing, a personalised disclosure, coping with HIV/AIDS, ARVs, nutrition and prevention. The programme urges young people to take responsibility for their actions and live healthy, positive lives, irrespective of their HIV status. All information is realistic, youth friendly and has been created for infected/affected youths by their peers. Presentations are followed by facilitated discussions on issues of importance. Handouts include a fact sheet and information on help lines/crisis centres. (Contact ICW for more information).



References

ICW, 2001, *ICW News* Issue 19, London: ICW
ICW, 2000, *ICW News* Issue 15, London: ICW
UNAIDS, 2003, *AIDS Epidemic Update 2003*,
Geneva: UNAIDS

ICW research programmes and workshops mentioned in this Vision Paper

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

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 HIV positive young
women is one of five ICW Vision Papers. This
series outlines ICW's position on: access to
care and treatment; participation and policy
making; gender equity and poverty; human
rights; and HIV positive young women. All
Vision Papers 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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