

INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS

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By the early 1990s, HIV-positive women were greatly frustrated by the appalling lack of support, information, and services available to women living with HIV worldwide and the lack of influence and input that they had on policy development. They were also dismayed at the ever-increasing numbers of women and girls contracting HIV and the negative experiences that they faced post-infection. HIV-positive women from around the world attending the VIII International Conference on AIDS held in Amsterdam, July 1992, decided to do something about these disparities and inequities. They shared stories and strategies for coping and devised action plans for the future. Wanting to maintain the momentum that they had gained through their meetings, they created the International Community of Women Living with HIV/AIDS (ICW) to address the issues crucial to all women worldwide living with HIV.

This profile describes the structure and vision of ICW as well as some of the activities that we undertake to ensure

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that women's rights in the context of HIV/AIDS are respected, protected, and fulfilled.

Structure of ICW

ICW is the only international network of HIV-positive women and has members in 134 countries. Our members are individual HIV-positive women who are often very involved with organizations and groups in their own countries. Our international support office in London serves our network of regional contacts, active members, international staff, and international governing body. The dedication of our small paid staff is matched by our highly motivated members, and it is their ongoing commitment that fuels the network.

Vision of ICW

- ICW envisions a world where all HIV-positive women:
1. **Have a respected and meaningful involvement at all political levels where decisions that affect our lives are being made.** ICW believes that when HIV-positive people are involved in all levels of decision-making of an organization, the organization is better able to respond to the concerns of people living with HIV/AIDS. For example, through personal experience, HIV-positive women and girls best understand the barriers that they face in accessing care and treatment and support. Thus, with first-hand knowledge of the needs of those living with HIV, members of ICW should be consulted on the development, design, and delivery of better ways of making treatment and care available to HIV-positive women and girls around the world. Groups and individuals concerned with these issues should work in creative, interactive, and participatory ways with HIV-positive women as well as with others who work directly with community members and other relevant groups to enable us to create "services to fit people" rather than "people to fit services." We believe that only through such collaborative efforts can we adequately address the barriers that prevent women and girls from accessing treatment and care and reduce the

number of HIV-positive women and girls who will get sick and die. It has now been over 10 years since 42 national governments declared at the Paris AIDS Summit that the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) principle is critical to ethical and effective national responses to the epidemic.¹ While this principle is widely accepted in theory, our experience has been that the views and voices of HIV-positive people — especially HIV-positive women and younger people — still tend to be overlooked or ignored.

2. **Have full access to care and treatment regardless of our gender, age, or lifestyle.** There is 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 gaining access to HIV drugs will be even more difficult for women and girls, particularly where drugs are not provided free of charge or where there is lack of confidentiality. Antiretroviral (ARV) treatment has turned HIV into a much more manageable chronic condition, which may no longer be a death sentence. ICW is keen to point out, however, that treatment is not just about providing ARV therapy; HIV-positive people also need nutritious food, a broad spectrum of care and support, and other medications to cope with opportunistic infections.
3. **Enjoy full rights irrespective of our culture, age, religion, sexuality, social or economic status/class, or race.** Many countries have agreed to international human rights standards that oblige them to respect and protect the rights of all people regardless of HIV status and gender. However, HIV-positive women, men, and children are often subjected to degrading and discriminatory treatment, which leads to blame, despair, isolation, and shame, and results in restricted opportunities in many areas of their lives. Moreover, gender inequalities in all areas of life promote 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. Human rights are indivisible and interdependent, so in order to fulfill one right, we need to be able to fulfill others. For example, respect for women's economic rights can put us in a stronger position to negotiate safe, pleasurable sexual relationships.

ICW's Action Steps to Ensure Respect, Protection, and Fulfillment of Women's Human Rights

Our activism and network-building are informed by the above principles. However, ensuring that the rights of HIV-positive women are respected, protected, and fulfilled requires hard work and much persuasion. If we are to be taken seriously, we need evidence both that our rights are being violated and that violating our rights perpetuates the epidemic and the stigma surrounding it. Research and testimonies from our members are part of a growing body of evidence.

Research and Testimonies

Many policy-makers and people working on HIV have told us to practice Abstinence, Be Faithful, and Use Condoms (ABC). If these same policy-makers were to listen to ICW members, however, they would realize that prescribing ABC is often unrealistic and irrelevant to our lives, as the following quote from an ICW member illustrates:

I was the youngest child in a large Muslim family ... I met the man who would be my husband. We dated for two years, and then got married. My husband got ill and went into the hospital for two months. Apparently, at that time he refused to have a test, and he went on refusing for a very long time. After, I got pregnant and was happy about that. But, after the delivery, I got ill. They did a test without my knowledge. And then the staff didn't treat me so well. And then, instead of telling me the result, they announced it to my husband! No one said anything about it to me. I had no idea what was going on. People began to treat me strangely, but I didn't know why. It was only four months later that my husband told me I was HIV-positive (Francophone Africa Voices and Choices Project).²

How can policy-makers tell us to practice ABC when they know very little about our lives? Without an understanding of the complex situations in which women live, such guidelines are meaningless for millions of women and girls worldwide. In the 1990s, this lack of knowledge was compounded by a notable absence of sensitive and relevant research on the experiences of positive women. ICW therefore decided to find out the experiences, needs, and wishes of HIV-positive women and created the Voices and Choices project. Because positive women feel more able to discuss difficult, sensitive issues with other positive women, the principal ethos governing the project was that it should be led by positive women and involve them in all stages of planning and implementation. In this collaboration between researchers and HIV-positive women, over 600 women were interviewed in Zimbabwe and Thailand between 1998 and 2001.

The interviews provided a great deal of important information, including the following: In both Thailand and Zimbabwe, most women had little or no knowledge of HIV transmission or risk factors before they were diagnosed HIV-positive. Married women, in particular, did not consider themselves at risk of infection, revealing a fundamental failure of HIV-prevention efforts. The study also confirmed that HIV-positive women continue to have sexual feelings and want sexual relationships after their HIV diagnosis. Many women, however, rarely receive support or advice about sexual matters after their diagnosis and find it impossible to insist on condom use. The research further revealed that divergent ideas about who should and who should not have children can leave HIV-positive women feeling caught between the pressure from health workers not to have children and from family to have children.

These and other studies underscore the fact that a lack of research on the sexual and reproductive health and rights of HIV-positive women is no longer an excuse to ignore us. However, the policy-makers still won't listen, as illustrated by the following statement:

I'm 24 now. I have a big mouth and I have a lot to say. I try to tolerate all sorts of people and I think I am tolerated in return. But I'm getting very tired. Sometimes

I think if people don't understand about HIV and AIDS now, they never will." (ICW member from Africa)

As long as we are not meaningfully involved in all aspects of the development, implementation, and evaluation of policies concerning our own lives, true change is unlikely to happen. Moreover, our members still lack the support and accurate information needed to make informed decisions about their lives and to act on the decisions they make.

Activism

Many ICW members know what they need and are aware that the little information and inadequate services they might be offered can, in fact, be detrimental to their sexual and reproductive health and rights. Furthermore, HIV-positive women may know whom they need to influence in order to bring about change but may not know how to take appropriate steps to affect change.

HIV-positive women activists often want to share their experiences as well as learn new advocacy skills. We have learned that developing advocacy skills and agendas requires solidarity and support networks. In order to encourage these efforts, we promote workshops that:

- expand outreach and create self-help groups to reduce feelings of isolation and hopelessness and increase the self-esteem of HIV-positive women,
- increase individual skills to strengthen networks, which will result in a wider pool of supported, knowledgeable, and effective women advocates,
- train HIV-positive women so that they can influence public opinion, policies, and service delivery at the local and national levels. This will result in service enhancement and a more supportive environment for HIV-positive women.

The Young Women's Dialogues

ICW's work with HIV-positive young women provides a good example of activist skill-building. Although their needs may be very different from those of older positive or non-positive women, young women, as a group, are rarely

given a platform to voice their priorities, and young women living with HIV and AIDS may be even further marginalized. While most efforts in the area of youth development focus on prevention, the reality is that there are millions of young women who are already HIV-positive. Young women are not simply older women packaged in smaller bodies. They are a vital part of the youth movement and play a significant role in African women's movements, in particular. Despite this, their activism and commitment to the fight against AIDS — in addition to their responsibilities to raise their siblings and children, educate communities about stigma and discrimination, and build their nations — are seldom recognized.

In 2004, ICW launched the Young Women's Dialogues (YWDs) to explore and address the specific needs and concerns of young HIV-positive women (aged 18–30) and to develop an appropriate advocacy agenda to promote the rights of young HIV-positive women. The program was initiated with a workshop involving 14 women from 10 countries in Eastern and Southern Africa. The workshop provided the basic tools for the participants to examine their own experiences through a gender-human rights lens in the context of the global HIV and AIDS pandemic and to draw out the main advocacy themes, develop messages, and outline the necessary steps to take their advocacy agenda forward. This regional meeting is being followed up by national workshops in several of the countries involved. In October 2004, the first of these took place in Swaziland, bringing together 20 young Swazi HIV-positive women to define and develop their advocacy agenda.

The methodology used in the YWDs is neither new to ICW nor restricted to the YWDs program. Rather, it can be adapted and applied to many different workshop-based research or advocacy programs. Elements of the same methodology were used in a more recent ICW project to monitor the political commitments of governments in response to the needs of HIV-positive women in Lesotho and Swaziland. The tools used by ICW in these programs for identifying what needs to change — and how and where those changes should take place — are context-specific in that they directly address the geographical, political, and social context

of the participants. They are based on the experience of participants; introduce or apply gender analysis to the experience; have as an end point an advocacy message, agenda, plan, or tool developed by and for use by the participants of the workshop; and enhance the capacity of workshop participants to mobilize other members of their community to similar activism.

Voces Positivas

The methodology described here was also used to develop advocacy skills and build an advocacy agenda by and for HIV-positive women across Latin America in 2003 in a project called *Voces Positivas*, which brought together HIV-positive women from 12 countries in Central America and the Caribbean to participate in a process of empowerment and training that they are now replicating in their home countries. Since that workshop the following have taken place:

- Participants from Nicaragua and the Dominican Republic have taken legal action against their respective governments in order to achieve universal access to treatment for all HIV-positive people.
- Participants from Costa Rica, Nicaragua, Guatemala, and El Salvador have obtained space in referral hospitals where they can meet other positive women and provide support and information. HIV-positive women in these countries have also trained health personnel on the specific needs of HIV-positive women.

Representation

The women that participate in these workshops are part of a growing group of activists who attend international, regional, and national events on behalf of the network and/or are members of committees and boards that make decisions that impact the lives of HIV-positive women and girls, such as the Country Coordinating Mechanisms (CCMs), which decide on the funding priorities of the Global Fund to Fight HIV/AIDS, Tuberculosis,

and Malaria (GFATM). These women highlight the experiences of HIV-positive women and girls across the ICW network and work to ensure that policies and practices support the rights and health of HIV-positive women and girls. We still struggle to counteract the view of many policy-makers, and even other activists, that the presence of any individual positive woman is enough, or that individuals can sufficiently represent HIV-positive women without the support and backing from our networks. They fail to recognize that our collective input as a network is vital if the stigma, discrimination, and gender inequality that fuels the spread of HIV is to be tackled systematically.

Our staff and members have attended many international, regional, and national conferences since the AIDS conference in Amsterdam in 1992, where ICW was established. Many of our staff and members had the opportunity to reach policy-makers and meet and share experiences with other HIV-positive women activists at the International HIV/AIDS conference in Bangkok in 2004. Our high visibility at Bangkok (ICW had a booth, ran a satellite meeting, held workshops, gave presentations, distributed publications, and managed to fund the attendance of over 40 ICW members and staff) is an indication of our growing confidence and strength.

We were disappointed, nonetheless, that although gender often figured in fine words spoken in plenary sessions, workshops, and events, the experiences, expertise, and ideas of HIV-positive women were often overlooked. A lot of time and energy was spent trying to make sure that HIV-positive women were represented in a variety of places where high-level discussions were being held; and although we can report some success, it was a tough, uphill battle. We will continue to try to reach the people who don't know, or sadly, do not care enough yet about the ongoing and very serious concerns facing women and girls who are HIV-positive. We hope that the next international AIDS conference in Toronto in 2006 will offer a chance for all to demonstrate a stronger commitment to the rights of HIV-positive women and girls.

Strengthening the Network: The Way Forward

The foundation and inspiration for all our work are our members: we are our members, and our numbers are growing daily. We will continue building the ICW network so it is increasingly recognized as a legitimate, organized force that represents the voice of HIV-positive women. We hope that strengthening the network from the local to the international level will enable HIV-positive women to identify and articulate common issues of greatest concern to them and to advocate for change at local, national, and international levels. This work will continue to be solidified by the efforts of our regional staff, contacts, and active members who work directly with individual members on a day-to-day basis so that we can draw on and support each other and so that our stories, information, and skills are shared with the world. This statement summarizes well what we want to achieve: "Much has and will continue to be learned about fighting HIV/AIDS and addressing important social issues like poverty by listening to the women and girls who are living with HIV and AIDS," ICW East Africa Regional Coordinator Lillian Mworeko said. "Women are the mother of the nation and deserve the care, support, and treatment policies that favor our well-being."

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