

THE POWER OF PARTICIPATION:

Women Leaders Speak

From a forthcoming review of women's leadership and participation in the AIDS response by UNIFEM and the ATHENA Network¹

"The only way you will empower me is if we sit at the table together and share our power."

– MariJo Vazquez, past Chair of the International Community of Women Living with HIV/AIDS (ICW) and Chair of the ATHENA Network

Clear calls for women's full participation in the AIDS response have been made at, and even before, the 1994 Paris AIDS Summit, whose Declaration pledged to

"...support initiatives to reduce the vulnerability of women to HIV/AIDS by encouraging national and international efforts, aimed at the empowerment of women ... by ensuring their participation in all the decision-making and implementation processes which concern them; and by establishing linkages and strengthening the networks that promote women's rights."

These calls have been repeated time and again not only by the United Nations General Assembly in the 2001 Declaration of Commitment on HIV/AIDS but also in numerous civil society statements and declarations such as the 1992 Twelve Statements of ICW, the 2002 Barcelona Bill of Rights, the 2005 Compact to End HIV/AIDS, the 2006 Johannesburg Position on HIV/AIDS and Women's and Girls' Rights in Africa, the 2006 Panama Declaration, the 2006 Blueprint for Action on Women and Girls and HIV/AIDS, the Nairobi 2007 Call to Action and the 2008 Women Demand Action and Accountability Now statement.

Yet, despite the increasing attention to and resources allocated for HIV and AIDS, as well as heightened debate around the "feminization" of the epidemic, women's full participation in the AIDS response has still not been realized. As the Honourable Charity Ngilu, Kenyan Minister for Health, stated at the 2007 International Women's Summit, *"My dear sisters, where policies are being made, our faces are not at those tables."*² This is particularly true for the

women who are the most affected by the epidemic, as for too long HIV-positive women have been invited only after agendas have been set or policy decisions taken. HIV-positive women leaders from Latin America have therefore boldly embraced the position of "nothing for us without us".

Obtaining information on who is participating where in the AIDS response at the national, regional or global level is a frustrating endeavour of stitching together data sources and asking individual questions of key informants. There is no consistent monitoring of involvement by key stakeholders in the formal and informal AIDS response, and the deeper question of meaningful participation by those most impacted by the epidemic is even more difficult to assess.

However, after an extensive review of existing documentation and lengthy in-depth interviews with key stakeholders in southern Africa, South Asia, Southeast Asia, Latin America and elsewhere, the evidence is clear. Although women are on the frontlines leading innovative initiatives that are central to the success of the AIDS response – as community-based care-givers, women's rights advocates and so on – they are not yet full participants in all levels of the response. For example, too few women have a seat on powerful mechanisms such as the National AIDS Coordinating Authority or the Country Coordinating Mechanism of the Global Fund to Fight AIDS, Tuberculosis and Malaria. Similarly, networks of women living with HIV, women's rights organizations and grassroots women's groups are not consistently represented either. Even when women or women's organizations hold seats, their participation is frequently contested and tokenistic.

At the opening of the International Women's Summit in Nairobi, Kenya in July 2007, Dr. Musimbi Kanyoro, speaking as the then World YWCA General Secretary, said, *"the leadership of positive women is not negotiable."* If women are leading the response in important ways, and if calls for women's full participation in the AIDS response have been made for over 15 years, why is so much of women's involvement invisible? And why are women, particularly the most affected women, still absent from formal and informal decision-making forums? *"Positive women bring a unique experience, inside knowledge and a drive to survive. Positive women need to be involved. Even though the rhetoric is changing, where is this happening?"*³

Situational Analysis

"First, we need to raise awareness on human rights, and also create an environment where women can come and talk freely and openly about their needs and rights. At the same time, we need to set up a policy that supports the involvement and participation of women. Also, we need to sensitize policymakers about the issue of women."

– Mony Pen, Cambodian Community Network of Women Living with HIV/AIDS⁴

Even as women actively strive to lead or even participate in civil society or governmental structures, significant barriers limit their capacity and reach. Central among these are the responsibilities women shoulder in their homes:

*"In households that are affected, everything is blamed on the women."*⁵

*"At the household level, I think the main problem is that as much as men say they are breadwinners, women are the backbone. The housework is done by women and they are unable to do their own things. They have too much work."*⁶

"I think many of the challenges women in the U.S. face are probably quite similar to women around the world. According to the Kaiser Family Foundation July 2007 report, 76 per cent of HIV-positive women have children under 18 to take care of, many are head of household and must work to

*support the family, living in poverty (64 per cent of HIV-positive women in the U.S. have incomes under \$10,000 compared with 41 per cent of HIV-positive men) with limited transportation available and are faced with intense stigma in deciding whether or not to step forward."*⁷

Similarly, the care-giving role that many women undertake in the context of HIV and AIDS is not sufficiently recognized as a core component of the response:

HIV-positive Women Leading the Response: Spotlight on the Positive Women's Network of India

"Our vision is that women living with HIV/AIDS and their children should have absolute right to live a life of dignity, in an environment free of any stigma and discrimination and that we succeed in mainstreaming our concerns to enable women to access their fundamental constitutional rights, especially the rights to equality, health, education, livelihood, to form association, enhance participation and be protected from violations and neglect."

Through mentoring by UNIFEM and building key non-governmental allies in the women's movement such as the Centre for Action Research, the Positive Women's Network (PWN+) plays a pivotal role in mobilizing HIV-positive women in India. PWN+ has partnered with the National AIDS Control Organization (NACO), the National Commission for Women, the Tamil Nadu State AIDS Control Society, UNIFEM, UNAIDS, UNDP, INP+, among many, along the way. By convening National Consultations with central stakeholders in the AIDS response, PWN+ has shaped an AIDS response in India that is responsive to, and led in tandem with, HIV-positive women.

*"...Until we get away from the concept that 'women's work' is voluntary or unpaid while men require payment, we will not enable a meaningful involvement of the people most disproportionately affected who also have the least resources."*⁸

Compounding the barriers raised by women's socially defined roles are the barriers women face when attempting to engage with the AIDS movement as a whole:

*"The movement of HIV-positive women emerged in a male-controlled context. In the beginning of the pandemic, and even until now in some regions of the world, AIDS activism is dominated by men. Sometimes these leaders have formed elites, and it is very difficult for women to be part of the decision-making levels. The first battle for gender equality has been inside the AIDS movement."*⁹

*"There is an AIDS power structure in the U.S. that does not include many women. Many men in policy and advocacy work have been doing AIDS work since the epidemic hit gay men over 20 years ago. They are skilled and well versed on how to gain entry into decision-making arenas. Many women do not have the experience, confidence and technology literacy to gain access to this arena."*¹⁰

Even when, for example, HIV-positive women are invited to a meeting or hold a seat in a decision-making forum:

*"The main challenge to participation and leadership in the response to HIV/AIDS at the social level is that besides taking care of our daily tasks, we have to go over the social structures set up by people who hold on to knowledge and who exercise power. They build their own interest groups, and in order to participate we need to raise awareness and win their trust. We participate but we do so in a situation of inequity, implementing first the actions that other people, with their own interests, decide for us."*¹¹

"Rarely, if ever, do those creating the policy, holding the meeting, developing the programme, ask: what are your priorities? Where do you think we should

start? What are the biggest challenges facing you at home?"¹²

Lastly, even within the community of women advocates, researchers and decision-makers, the heterogeneity of women's lived experience is frequently overlooked and the critical alliances across movements do not consistently exist. For example, sex worker leaders commented after the 2006 International AIDS Conference that it was the first time they had been included in women's rights sessions. Despite the violence faced by lesbian women, in South Africa for example, in the context of HIV and AIDS, this issue is not consistently on the women and HIV agenda. Women who use drugs struggle to add a gender perspective to harm reduction, and their particular concerns are too frequently overlooked as well. The manner in which young women struggle to have a voice and be recognized in the women's sector is one more case in point. Further, "it has been rare for women's organizations to stand by positive women's organizations...hard to get support by the women's movement"¹³ for HIV-positive women. These are only a few ways in which, even across overlapping and related movements, there are stronger alliances to be built and critical gaps to fill.

Challenges Across Continents

The challenges women face in order to participate in both formal and informal structures in the AIDS response are consistent across continents, even if variable in degree. Women's responsibilities within their homes limit their ability to travel for extended lengths of time to meetings or trainings. The space afforded HIV-positive women in the AIDS movement has been contested. A key informant from the National Movement of Positive Women Citizens in Brazil noted:

*"We still have many spaces to conquer. Recognition that we need to have specific spaces because we have specific requirements is still not a matter of consensus inside the AIDS movement."*¹⁴

Investment in building the strategic capacity of the most affected women has been inconsistent. Projects and programmes to address women in the context of HIV and AIDS

are too frequently focused on women as objects of services, not as agents of change.

*"They give us money but do not include us. They do not ask us what the issue is. ... I'm not sure they will support us long term. For women to be empowered, they need long-term support from donors."*¹⁵

Resources are donor-driven, and organizational structures can lack attention to gender dynamics.

*"We are doing work supporting most at risk women, but programme staff for this are mostly men. It's similar to other organizations, both non-governmental and governmental. ... At high levels, there are more male staff than female; at grassroots levels, there are more women. It can appear as: Men are thinkers, decision makers, and women are doers."*¹⁶

Broader alliances between the women's rights movement and the HIV-positive women's movement have been slow to form. Women, particularly those most affected by HIV and AIDS, have had to struggle constantly for a voice in agenda-setting and policy-making. Transparent entry points frequently do not exist.

*"We need the voice of women at the table, especially women living with HIV. But how do we do that? How do we get involved say, at NIH? ... No one answers me. I plan to go to [Washington] DC in April to speak to people about this – but how do I get involved and who do I speak to?"*¹⁷

The pace of communication and decision-making at the global level far outstrips the ability of women with limited Internet access or ability to converse easily in English to keep up. Structural barriers go hand in hand with broader policy and practice that are not inclusive. HIV-positive women or their networks are invited late to meetings after agendas are set or into processes after guidance or policy has been formulated. Thus they are constantly placed in the role of reaction, disappointment and complaint, rather than in a position of proactive constructive and creative

Achieving the Power of Participation: Recommendations²¹

- 1) Recognize affected women, such as HIV-positive women, home-based caregivers and young women, as key stakeholders in the AIDS response through creating formal places for real participation and leadership in decision-making bodies, as these mechanisms are places of power;
- 2) Ensure democratic processes for selecting civil society representation and enable true representation through providing support for consultation and collaboration;
- 3) Ensure that national plans and programmes on HIV and AIDS prioritize women's needs and priorities as identified by women through consultation and engagement;
- 4) Invest in organizations and initiatives led by and with HIV-positive women;
- 5) Invest in developing a new cadre of women leaders, particularly HIV-positive women, at local and national levels;
- 6) Simplify funding mechanisms so as to facilitate greater access to resources by women's organizations, especially community-based women's organizations, and target resources to these organizations;
- 7) Support programmes that address the immediate needs of women, including increased access to HIV prevention, treatment, care and support services;
- 8) Prioritize gender expertise in all aspects of the AIDS response, including in formal decision-making bodies and funding mechanisms;
- 9) Increase women's awareness and understanding of human rights, including the right to full and meaningful participation;
- 10) Promote the participation, empowerment and leadership of women at all levels of society.

contribution. Similarly, women are invited to speak to “women’s issues” only and not to address the broader policy directives under consideration. Participation is seen as a privilege, rather than as a right, as meaningful, sustained engagement.

Roadmap for Action

So what is the roadmap for realizing the meaningful involvement of women in all aspects of the AIDS response and for them to have the full power of participation?

“We will never see a reduction in new infections and deaths without investing in the strategic capacity of the most directly affected, HIV-positive women.”¹⁸

Advancing women’s leadership and participation in the AIDS response requires concrete steps to address the obstacles they face as well as longer-term commitments to leadership development, training and resource allocation.

“One [strategy] is to understand the need for affirmative action to ensure there are always two places at the table

for persons living with HIV, one woman and one man. Many of the major organizations do not understand the need for women to be represented by themselves, but issues for women are often very different from those addressed by other constituencies ... Secondly, we must ensure resources are put in the hands of positive women’s networks and the vast army of women who provide the majority of treatment, care and support services without material support.”¹⁹

- 1) Monitor the “full and active participation of people living with HIV, vulnerable groups, most affected communities”²⁰ in the response, particularly as it pertains to women living with and affected by HIV;
- 2) Collect sex disaggregated data on participation and implement an assessment of the extent to which women’s participation is indeed meaningful and a part of leadership to better guide policy development and resource allocation;

- 3) Develop definitions of and standards for meaningful participation through consultation with women, most importantly with HIV-positive women and their networks;
- 4) Strengthen the capacity of affected women, particularly HIV-positive women, to participate fully in the HIV and AIDS response through leadership training, sustained technical support and mentorship;
- 5) Document and disseminate successful strategies and innovative initiatives to strengthen and promote the leadership and participation of HIV-positive women;
- 6) Identify strategic areas for advocacy and influence, such as increasing the participation of HIV-positive women and women’s rights organizations in Country Coordinating Mechanisms of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

¹ This summary has been drawn from an extensive nine-month global review of women’s leadership and participation in the AIDS response. The full report is forthcoming. Thank you to UNDP for its support. Thank you to the organizations and individuals who gave significant time and shared their expertise so generously. Thank you especially to Johanna Kehler, Alessandra Nilo, Josefina Oraa, Betsi Pendry, Marion Stevens, Reshma Trasi, MariJo Vazquez, and Alice Welbourn. Thank you also to ICW for its leadership and to the International Center for Research on Women (ICRW) and The Centre for Development and Population Activities (CEDPA) who led a series of in-depth interviews with women leaders.

² Speech at the International Women’s Summit: Women’s Leadership on HIV and AIDS, Nairobi, Kenya, July 2007.

³ Beri Hull, International Community of Women Living with HIV/AIDS (ICW), Interviewed 6 February 2008.

⁴ Mony Pen, Cambodian Community Network of Women Living with HIV/AIDS, Interviewed by ICRW and CEDPA 4 February 2008.

⁵ Asha Juma, Kenya, Interviewed by ICRW and CEDPA 1 February 2008.

⁶ Ignatia Jwara, Gender AIDS Forum, Interviewed by ICRW and CEPA 6 February 2008.

⁷ Maura Riordan, WORLD, Personal communication 11 February 2008.

⁸ Lynde Francis, The Centre, Personal communication April 2008.

⁹ Violeta Ross, ‘A Bridge Needs Two Sides’, presented at the Global Round Table, Countdown 2015 Sexual and Reproductive Rights for All, London, 2004.

¹⁰ Maura Riordan, WORLD, Personal communication 11 February 2008.

¹¹ ICW Brazil, Personal communication 18 February 2008.

¹² Luisa Orza and Jennifer Gatsi Mallet, ‘Thinking Positive’, 30 November 2007, openDemocracy, available at: http://www.opendemocracy.net/article/5050/16_days/hiv_aids_namibia.

¹³ Undisclosed informant, Interviewed 15 February 2008.

¹⁴ Alessandra Nilo, ‘Case Study of Women’s Leadership and Participation in the AIDS Response in Brazil’ from forthcoming review.

¹⁵ Mony Pen, Cambodian Community Network of Women Living with HIV/AIDS, Interviewed by ICRW and CEDPA 4 February 2008.

¹⁶ Hoang Thi-Le An, Vietnam, Interviewed by ICRW and CEDPA 31 January 2008.

¹⁷ Shannon Behning, Women’s Lighthouse Project, Interviewed by ICRW and CEDPA 5 February 2008.

¹⁸ Terry McGovern, Ford Foundation, Interviewed 18 March 2008.

¹⁹ Lynde Francis, The Centre, Personal communication April 2008.

²⁰ United Nations General Assembly, ‘Declaration of Commitment on HIV/AIDS’, A/RES/S-26/2, 27 June 2001, <http://www.un.org/ga/aids/docs/aress262.pdf>.

²¹ These recommendations build on those developed by the Huairou Commission, ICW, VSO and the World YWCA, among others, as well as from the numerous calls to action and statements developed by civil society on this topic. Number 10 is taken directly from the Nairobi Call to Action.