

**TRANSFORMING THE NATIONAL AIDS RESPONSE:  
ADVANCING WOMEN'S LEADERSHIP AND PARTICIPATION**

**Executive Summary**

*"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

Women's leadership and participation are central to transforming the HIV and AIDS response at national and global levels. Yet, despite international consensus on the need for women's participation as well as donor and civil society calls for enhanced focus and resources on gender equality and women's human rights, women's full participation in the AIDS response has not been realized.

Data and analyses of women's representation and participation, including networks of women living with HIV, women's rights organizations or grassroots women, are not readily available at the country, regional or global level. With very little consistent monitoring of involvement by key stakeholders, obtaining information on who is participating where, in the formal and informal AIDS response is challenging. The deeper question of meaningful participation by those most impacted by the epidemic is even more difficult to assess.

In the absence of relevant data and to establish a foundation for further research, UNIFEM, in partnership with the ATHENA network, commissioned a review of women's leadership and participation in the AIDS response at the national and global level.

***Transforming the National AIDS Response: Advancing Women's Leadership and Participation*** is an effort to better understand where and in what ways, particularly women and those most affected by the epidemic, are participating in the response. The study also assesses the opportunities for and challenges to their participation and strategies that can be used to advance their full and meaningful participation at all levels.

**Methodology:** In-depth interviews and consultations with more than 100 key informants, including institutional leaders and decision-makers, were held in southern Africa, South Asia, Latin America, and elsewhere. The analysis was also informed by an extensive literature review, documentation of country case studies, and the responses to and results of a survey disseminated to global and regional networks. Lastly, the review benefited from and drew on a series of in-depth interviews of 25 women leaders from around the world conducted by the International Center for Research on Women (ICRW).

**Key Findings**

Five key findings emerged from this review:

- The involvement of affected communities, particularly women living with HIV, young women and grassroots women, plays a critical role in defining sound and effective policies and programmes that respond to women's realities, needs and vulnerabilities. At present, too few women sit on powerful

agenda setting and policy-making mechanisms such as the National AIDS Coordinating Authority or the Country Coordinating Mechanisms (CCMs) of the Global Fund to Fight AIDS, Tuberculosis and Malaria. According to 2009 Global Fund data, the proportion of women represented on CCMs hovers around 34% globally; of the chairs and vices chairs of CCMs, the proportion of women is 20- 25% respectively. Even less represented on CCMs are people living with HIV- 8 % on CCMs. And for key affected populations the global participation rate is 1%.

- Women, especially those affected, face significant barriers to their participation. Interviews cited gender norms (79%), stigma (58%), lack of access to information (46%) and resources (58%), the burden of care-giving and women's multiple responsibilities in the home (46%), illiteracy (46%) and low self-esteem (25%) as key constraints to their full and meaningful participation.
- Broader alliances between the women's rights movement and the HIV-positive women's movement are needed. Unrealized potential exists for strengthening women's leadership and participation in the AIDS response, particularly those most affected by HIV/AIDS.
- Participation is treated as a privilege rather than as a right. When women do acquire a "seat at the table", challenges to their meaningful involvement include lack of transparent entry points, lack of capacity to substantively participate in formal processes, competing agendas in formal decision-making spheres and a lack of critical alliances. Moreover, women are invited to speak to "women's issues" only and rarely address broader policy considerations.
- Sustained investment in women as agents of change and in women's mobilization, such as support for HIV-positive women's networks, has proven successful in diverse regions and settings.

## Conclusion

There is an urgent need for dedicated commitment to developing women as agents of change and active partners in defining and implementing solutions from the community to the global levels. Advancing women's leadership and participation in the AIDS response requires concrete steps to address the various systemic obstacles they face. There is also a need to foster longer term commitments to increase resources to reducing women's vulnerability to HIV and AIDS.

The study outlines ten **actionable** recommendations for governments, donors, and other institutional leaders in the AIDS response. They can also be used as part of a larger advocacy agenda for civil society stakeholders, particularly affected communities and people living with HIV.

## Recommendations

1. Recognize affected women, such as HIV-positive women, home-based caregivers, and young women, as key stakeholders in the AIDS response. Reserve formal places for women's meaningful participation and leadership in decision-making bodies, such as on the Country Coordinating Mechanisms of the Global Fund to Fight AIDS, Tuberculosis and Malaria.
2. Develop definitions and standards for meaningful participation through consultation with women, particularly HIV-positive women and their networks.
3. Monitor the "full and active participation of people living with HIV, vulnerable groups, most affected communities" in the HIV and AIDS response, with special attention to women living with and affected by HIV.

4. Ensure democratic and transparent processes for selecting civil society representation by providing support for consultation and collaboration.
5. Strengthen the capacity of affected women, particularly HIV-positive women and young women, to participate in the HIV and AIDS response. Leadership training, sustained technical support and mentorship are essential to promote a new cadre of women leaders at local and national levels.
6. Increase women's awareness and understanding of human rights, including the right to full and meaningful participation.
7. Invest in organizations and initiatives led by and with HIV-positive women and facilitate greater access to resources by women's organizations, especially community-based ones.
8. Document and disseminate successful strategies and innovative approaches to strengthen and promote the leadership and participation of affected women, particularly HIV-positive women and young women.
9. Ensure that national plans and programmes on HIV and AIDS prioritize women's needs and priorities as identified by women themselves through consultation and engagement. Respond to the immediate needs of women, including increased access to HIV prevention, testing, treatment, care and support services.
10. Strengthen gender expertise within formal decision-making bodies and funding mechanisms involved in the response to HIV and AIDS.