Transforming the National AIDS Response

Advancing Women's Leadership and Participation







and the Empowerment of Women



UNIFEM (now UN Women) is the women's fund at the United Nations. It provides financial and technical assistance to innovative programmes and strategies to foster women's empowerment and gender equality. Placing the advancement of women's human rights at the centre of all of its efforts, UNIFEM (now UN Women) focuses on reducing feminized poverty; ending violence against women; reversing the spread of HIV/AIDS among women and girls; and achieving gender equality in democratic governance in times of peace as well as war.

UNIFEM (now UN Women) brings gender equality and human rights perspectives to its work on women and HIV and AIDS, spearheading strategies that make clear links to underlying factors such as violence against women, feminized poverty and women's limited voice in decision-making. UNIFEM (now UN Women) has contributed to integrating gender aspects into the plans and policies developed by national AIDS councils in more than 35 countries as well as into regional programmes.



The ATHENA Network was created to advance gender equity and human rights in the global response to HIV and AIDS. Because gender inequity fuels HIV and HIV fuels gender inequity, it is imperative that women and girls – particularly those living with HIV – speak out, set priorities for action and lead the response. The Barcelona Bill of Rights, promulgated by partners at the 2002 International AIDS Conference, is ATHENA's framework for action. Its mission is to:

- Advance the recognition, protection and fulfilment of women's and girls' human rights, comprehensively and inclusively, as a fundamental component of the response to HIV and AIDS.
- Ensure gender equity in HIV-related research, prevention, diagnosis, treatment, care and development interventions based on a gendered analysis.
- Promote and facilitate the leadership of women and girls, especially those living with HIV, in all aspects of the response to HIV and AIDS.
- Bridge the communities around the world that are addressing gender, human rights, sexual and reproductive health and rights, and HIV.

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Last, but certainly not least, tribute must be paid to the extraordinary women and men who work tirelessly to realize a world where all women enjoy the right to participate and lead in all aspects of their lives, as well as to the institutional contributors to this endeavour:

ATHENA Network

AIDS Legal Network Coalition for a Blueprint for Action on Women and Girls and HIV **Huairou Commission** Ford Foundation Gestos Global Coalition on Women and AIDS (GCWA) Global Fund to Fight AIDS, Tuberculosis and Malaria Secretariat International Community of Women Living with HIV/AIDS (ICW) **ICW Latina** International Planned Parenthood Federation (IPPF) Living Together Institute Namibia Women's Health Network (NWHN) Open Society Institute (OSI) Open Society Initiative for Southern Africa (OSISA) Salamander Trust Sexual Violence Research Initiative (SVRI) Society of Women and AIDS in Africa (SWAA) Thai Women and AIDS Task Force The Joint UN Programme on HIV/AIDS (UNAIDS) The Women's Collective (TWC) **United Nations Development** Programme (UNDP) United Nations Population Fund (UNFPA) UNIFEM (now UN Women) **Regional Offices** Volunteer Services Organisation (VSO) Women WON'T Wait (WWW) Women Organized to Respond to Life-threatening Disease (WORLD)

World Young Women's Christian Association (World YWCA)

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Acronyms and abbreviations

CCM Country Coordinating Mechanism

CEDPACentre for Development and Population Activities

GCWAGlobal Coalition on Women and AIDS

GIPAGreater Involvement of People Living with HIV/AIDS

ICRWInternational Center for Research on Women

ICWInternational Community of Women Living with HIV/AIDS

M&E monitoring and evaluation

MNCP Movement of Positive Women Citizens, Brazil

NACA National Agency for the Control of AIDS, Nigeria

NGO non-governmental organization

NSPNational Strategic Plan for STIs and HIV and AIDS 2007–2011, South Africa

OSISA Open Society Initiative for Southern Africa

PMTCT Prevention of Mother-to-Child Transmission

PWMCpositive women monitoring change

PWN+ Positive Women's Network, India

RNP+National Network of People Living with HIV, Brazil

SAATHII Solidarity and Action Against The HIV Infection in India

SANACSouth African National AIDS Council

TRPTechnical Review Panel, Global Fund to Fight AIDS, Tuberculosis and Malaria

UNAIDS Joint United Nations Programme on HIV/AIDS

UNDP United Nations Development Programme

UNIFEM United Nations Development Fund for Women

Methodology

Data and cross-cutting analyses of women's representation and participation – including networks of women living with HIV, women's rights organizations or grass-roots women – are not readily available at the country, regional or global level. In order to begin to fill these information gaps and build a foundation for further research, UNIFEM (now UN Women) commissioned a review of women's leadership and participation in the AIDS response at the national and global level in partnership with the ATHENA Network.

Extensive consultations were held with institutional leaders such as UN partners, the Global Fund to Fight AIDS, Tuberculosis and Malaria and the Global Coalition on Women and AIDS (GCWA) as well as civil society leaders and stakeholders at the community, national, regional and global levels. In addition, specific input was sought from Brazil, India and South Africa to reflect the variation in national level experiences.

In-depth interviews were held with more than 100 key informants and decision-makers by the lead researcher and author, Tyler Crone (see Annex I). HIV and gender expert Alessandra Nilo (Brazil), gender expert Josefina Oraa (India) and women's health expert Marion Stevens and human rights expert Johanna Kehler (South Africa) undertook in-depth interviews with key country-level stakeholders in their respective countries. In addition, this report drew on a series of in-depth interviews with 25 women leaders from around the world conducted by the International Center for Research on Women (ICRW) and the Centre for

Development and Population Activities (CEDPA) under the 'Advancing Women's Leadership and Advocacy for AIDS Action' initiative.

The interview questionnaire was designed to assess respondents' perceptions of challenges and opportunities women face with regard to participation and leadership in the response to HIV and AIDS, strategies to enhance women's participation and leadership, the role of civil society leadership on women and AIDS, and capacity needs to strengthen women's leadership and participation. The detailed interview template is included in Annex I.

An extensive literature review as well as the results from a global survey disseminated through listserves and global and regional networks also informed the analysis. More than 100 responses were received to the global survey, which was designed to gather information on challenges and opportunities for women's participation and leadership as well as on their levels of participation and leadership in various country mechanisms that determine programmes, policies, priorities and funding. The survey is included in Annex I.

Lastly, extensive effort was invested in developing case studies that document and analyse recent experience on enhancing women's participation, especially those living with HIV, in national and global AIDS fora. All research and findings underwent a key stakeholder validation process. The final report was authored by Tyler Crone and edited by Nazneen Damji and Johanna Kehler.



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