





UNIFEM 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 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 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 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.

# Transforming the National AIDS Response

Advancing Women's Leadership and Participation



ATHENA



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# Acronyms and abbreviations

<b>CCM</b>	Country Coordinating Mechanism
<b>CEDPA</b>	Centre for Development and Population Activities
<b>GCWA</b>	Global Coalition on Women and AIDS
<b>GIPA</b>	Greater Involvement of People Living with HIV/AIDS
<b>ICRW</b>	International Center for Research on Women
<b>ICW</b>	International Community of Women Living with HIV/AIDS
<b>M&amp;E</b>	monitoring and evaluation
<b>MNCP</b>	Movement of Positive Women Citizens, Brazil
<b>NACA</b>	National Agency for the Control of AIDS, Nigeria
<b>NGO</b>	non-governmental organization
<b>NSP</b>	National Strategic Plan for STIs and HIV and AIDS 2007–2011, South Africa
<b>OSISA</b>	Open Society Initiative for Southern Africa
<b>PMTCT</b>	Prevention of Mother-to-Child Transmission
<b>PWMC</b>	positive women monitoring change
<b>PWN+</b>	Positive Women’s Network, India
<b>RNP+</b>	National Network of People Living with HIV, Brazil
<b>SAATHII</b>	Solidarity and Action Against The HIV Infection in India
<b>SANAC</b>	South African National AIDS Council
<b>TRP</b>	Technical Review Panel, Global Fund to Fight AIDS, Tuberculosis and Malaria
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNDP</b>	United Nations Development Programme
<b>UNIFEM</b>	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 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.



# Chapter 1

## Introduction

*“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*

The critical importance of women’s leadership and participation is increasingly being recognized and advanced as central to transforming the HIV and AIDS response. The *Agenda for Accelerated Country Action for Women, Girls, Gender Equality and HIV*, launched by UNAIDS in March 2010, champions “strong, bold and diverse leadership for women, girls and gender equality, for their participation in decision-making, in the context of HIV” (see Box 1).<sup>1</sup> The landmark 2007 International Women’s Summit: Women’s Leadership Making a Difference on HIV and AIDS, convened by the World YWCA and the International Community of Women Living with HIV/AIDS (ICW), is another example of progress in this area – as is the successful launch of the Global Coalition on Women and AIDS as a partnership of non-governmental organizations (NGOs) and UN entities in 2004 (see Box 1). Similarly, principal funders in the AIDS response, the Global Fund to Fight AIDS, Tuberculosis and Malaria and PEPFAR, are taking significant steps to engender their work.

This report is an effort to better understand where and in what ways women, particularly those most affected by the epidemic, are participating in the response; the opportunities for and challenges to their participation; and strategies that can be implemented and steps taken to advance their full and meaningful participation at all levels in order to ensure that the response to

HIV and AIDS reflects women’s priorities and needs.

Drawing on the analysis of more than 100 key informant interviews as well as 100 global survey responses, five key findings have emerged from this review:

- 1) The involvement of affected communities, particularly women living with HIV, young women and grassroots women, plays a critical role in defining sound policies and programmes.
- 2) Unrealized potential exists for strengthening women’s leadership and participation in the AIDS response, particularly by those most affected by HIV and AIDS.
- 3) Significant barriers that prevent this participation, particularly of those most affected, include gender norms, stigma and discrimination, lack of access to resources, the burden of care and multiple responsibilities in the home, lack of access to information, lack of formal education and training, poor self-esteem and gender-based violence.
- 4) Even when women obtain 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.

“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.”

— *Terry McGovern, Ford Foundation*

## Bringing women to the table

### UNAIDS Agenda for Accelerated Country Action for Women, Girls, Gender Equality and HIV

Recognizing the importance of greater action to meet the urgent needs of women, UNAIDS and UNIFEM along with key experts, civil society and government partners, produced a framework to guide UN agencies at the country level to:

- 1) “Jointly produce information on and a better understanding of the specific needs and rights of women and girls in the context of HIV, so that national AIDS programmes can respond more effectively.
- 2) Turn political commitments into increased resources and effective actions, so that HIV programmes better respond to the needs of women and girls.
- 3) Mobilize leaders to create safer environments in which women and girls can feel empowered to exercise their human rights.”<sup>2</sup>

This framework is intended to inspire innovations to expand HIV-positive women’s voices in the HIV response.

### The Global Coalition on Women and AIDS

The Global Coalition on Women and AIDS (GCWA) is a worldwide alliance of civil society groups, networks of women living with HIV, women’s organizations, AIDS service organizations and the UN system committed to strengthening AIDS programming for women and girls. The GCWA seeks to mobilize partners, decision-makers and society at large to advance the AIDS response for women and girls at national level; influence the response through placing emerging or unaddressed issues firmly on global and national agendas; act by reaching out to a broad array of partners to gather the technical resources needed by countries and communities to address the programming challenges; and empower women and girls to participate in and influence national responses and build accountability for results. It is particularly committed to engaging women and girls living with HIV as core partners in shaping its advocacy. The GCWA advocates for the involvement of women and girls as decision-makers, contributors and implementers of action as well as beneficiaries of support.

- 5) 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.

Chapter 2 looks at the rationale for and status of women’s participation in the AIDS response. It highlights the international declarations and commitments that have been made related to women’s participation in decision-making as well as civil society calls for action. It also

provides an overview of the challenges to women’s full and meaningful participation.

Chapter 3 examines five case studies, three on specific countries (Brazil, India and South Africa), one on the Global Fund to Fight AIDS, Tuberculosis and Malaria and one on accountability and monitoring. The first study, on South Africa, demonstrates the challenge of full involvement and meaningful participation in an evolving political landscape, even when formal structures are established to facilitate this. Next, the study on Brazil explores the importance of bridging

movements, and the need for broader recognition of the space HIV-positive women require within formal governmental structures and social movements. The study on India examines the strategies employed to organize and collectively influence the AIDS response by women living with HIV and shares key lessons. The fourth study provides a snapshot of the Global Fund, outlining the opportunities for the strengthened engagement of key stakeholders and the robust involvement of women in this essential funding mechanism. Lastly, the fifth study focuses on the meaningful engagement of women, particularly positive women, in the monitoring and evaluation of HIV policies and programmes.

The report illustrates some of the promising approaches that have been

used by community, national and regional organizations to bolster women's leadership and participation. It also features comments from women leaders in HIV and AIDS as a means of exploring the question of meaningful involvement from different perspectives and through a variety of mechanisms in the AIDS response.

Finally, the last chapter sets out a number of recommendations for policy-makers, programme implementers and a broad range of stakeholders to ensure the promotion and full, meaningful involvement of women at all levels within the structures and processes of the HIV and AIDS response. This report is intended to spark greater attention to and inclusion of women, particularly those most affected by HIV and AIDS, as agents of change and as experts through their experience.

WHERE

IS

GIPPA?

DON'T

ISOLATE

US

OUR WORK?

## Chapter 2

# Rationale for and Status of Women's Participation in the AIDS Response

### Women's right to participate in HIV and AIDS decision-making

International agreements, including the 1995 Beijing Platform for Action, clearly establish women's right to participate fully in formal and informal decision-making structures. Women's right to participate in HIV decision-making in particular is also recognized in several international HIV and AIDS policies and frameworks, including the 1994 Declaration from the Paris AIDS Summit and the 2001 Declaration of Commitment on HIV and AIDS from the historic United Nations General Assembly Special Session on HIV and AIDS (see Box 2). Civil society statements – such as the 1992 Twelve Statements of the International Community of Women Living with HIV/AIDS (ICW), the 2002 Barcelona Bill of Rights, the 2005 Compact to End AIDS, the 2006 Panama Declaration of ICW Latina, the 2007 Nairobi Call to Action, the 2008 Women Demand Action and Accountability Now Statement and the 2010 Women ARISE platform – have affirmed time and again that

*"[b]ecause gender inequality fuels HIV/AIDS and HIV/AIDS fuels gender inequality, it is imperative that women and girls speak out, set priorities for action and lead the global response to the crisis."<sup>3</sup>*

Yet, despite the clearly established right of women to fully participate in HIV and

AIDS decision-making and leadership, this has not yet been realized. Women, particularly those most affected by the epidemic, do not shape the AIDS response globally or nationally with the same influence, weight and reach as men.

### Why women's participation is essential

With continued new infections among women, an increase in the proportion of women living with HIV in regions such as the Caribbean and Asia and the disproportionate burden women shoulder from the epidemic, national governments and the global community have a clear mandate to embrace, engage and strengthen the leadership and participation of women and girls in the response. Involving women, particularly those most affected by the epidemic, is both a means of empowerment and essential to ensuring that policies and programmes adequately and effectively respond to the realities women face.

As urged by the Executive Director of UNAIDS, Michel Sidibe, at the Fifty-fourth session of the Commission on the Status of Women, "...we need to invest much more in the participation and leadership of women and girls living with HIV, so that they can gain access to decision-making spaces and become 'agents of change' to guide all stages of planning and implementation of our response to AIDS".<sup>12</sup>

"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/AIDS*

## Women's right to participate in HIV and AIDS decision-making

### Declarations and Commitments

The **Paris Declaration**, Paris AIDS Summit, 1 December 1994 declares that governments:<sup>4</sup>

IV. Are resolved to step up international cooperation through the following measures and initiatives:

- Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all – national, regional and global – levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.
- Support initiatives to reduce the vulnerability of women to HIV/AIDS by encouraging national and international efforts, aimed at the empowerment of women: by raising their status and eliminating adverse social, economic and cultural factors; 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.

The **Beijing Declaration and Platform for Action**, United Nations Fourth World Conference on Women, 15 September 1995 affirms that:<sup>5</sup>

1. Women's empowerment and their full participation on the basis of equality in all spheres of society, including participation in the decision-making process and access to power, are fundamental for the achievement of equality, development and peace; ...

The **United Nation General Assembly Declaration of Commitment on HIV/AIDS**, 27 June 2001, calls for:<sup>6</sup>

33. Acknowledging the particular role and significant contribution of people living with HIV/AIDS, young people and civil society actors in addressing the problem of HIV/AIDS in all its aspects and recognizing that their full involvement and participation in design, planning, implementation and evaluation of programmes is crucial to the development of effective responses to the HIV/AIDS epidemic;

37. By 2003, ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS that address the epidemic in forthright terms; confront stigma, silence and denial; address gender and age-based dimensions of the epidemic; eliminate discrimination and marginalization; involve partnerships with civil society and the business sector and the full participation of people living with HIV/AIDS, those in vulnerable groups and people mostly at risk, particularly women and young people; are resourced to the extent possible from national budgets without excluding other sources, inter alia, international cooperation; fully promote and protect all human rights and fundamental freedoms, including the right to the highest attainable standard of physical and mental health; integrate a gender perspective; address risk, vulnerability, prevention, care, treatment and support and reduction of the impact of the epidemic; and strengthen health, education and legal system capacity;

### Civil Society Calls for Action

The 1992 *Twelve Statements of ICW*, to improve the situation of women living with HIV and AIDS throughout the world, call for:

10. Decision making power and consultation at all levels of policy and programmes affecting us.

The 2002 *Barcelona Bill of Rights* states that women and girls have the right:<sup>7</sup>

To lead and participate in all aspects of politics, governance, decision-making, policy development and programme implementation.

The 2005 *With Women Worldwide: A Compact to End HIV/AIDS* calls on decision-makers to:<sup>8</sup>

**Expand decision-making:** Ensure that women infected and affected by HIV/AIDS, and women's health and rights advocates, are full participants in decision-making, especially at the highest levels, so that decisions reflect the realities and needs of women.

The 2006 *Panama Declaration* states:<sup>9</sup>

The path must, absolutely, include people living with HIV and AIDS working alongside the most powerful forces uniting all nations... In particular, this must include women, young girls and adolescents who are the victims of poverty and exclusion, migrant women, women who are heads of household, drug users, sexual workers, refugees, women in confinement and women from indigenous groups ... We want 'nothing for us without us'.

### The Nairobi 2007 Call to Action

outlines:<sup>10</sup>

By taking leadership into our hands and uniting in strength as a movement of women, we can lead the change we wish to see in the world. ... The ten critical areas for change are:

1. Developing the leadership of women and girls to respond to HIV and AIDS...
2. Ensuring the meaningful involvement of women infected and affected by HIV in relevant decision-making, respecting our right to self determination and enabling our participation in the development of AIDS strategies, programming and decision-making bodies.

### The 2008 Women Demand Action and Accountability Now Statement

articulates:<sup>11</sup>

In all aspects of national, regional and global AIDS responses it is essential to ensure that the voices and experience of people living with HIV and AIDS – especially women and girls whose voices are too often silenced – are given prominent position in designing and scaling up the global AIDS response. We ask that specific mechanisms for civil society's participation be set up; including ensuring women's groups have a seat at the table when it comes to devising global, national and local AIDS strategies.

This echoes the statement by Peter Piot, former Executive Director of UNAIDS, that, *“This trend of feminization is transforming the AIDS epidemic and now it must equally transform our response to the epidemic. Women must be at the table where AIDS programmes are being decided”*.<sup>13</sup>

Leading human rights and HIV advocate Louise Binder, who has been at the forefront of the movement of persons living with HIV to increase access to HIV prevention, treatment and care globally, explains:

*“Put simply, women know the disease and the conditions of their lives in ways that no one else can fathom. Thus, their input is essential to ensure that policies and programmes that may be well intentioned and logical theoretically can be implemented on a practical grass-roots level. We can identify barriers and help solve them through policy or programme changes or through education and capacity building on the ground. We are also knowledge exchange brokers to ensure sustainability and change as required to meet changing needs and conditions.”*<sup>14</sup>

### **The current situation**

Although there has been increasing attention to and resources allocated for HIV and AIDS, as well as heightened debate around the ‘feminization’ of the epidemic, women are still not full participants in the AIDS response. As the Honourable Charity Ngilu, former 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”*.<sup>15</sup> This is particularly true for the women who are the most affected by the epidemic. For too long HIV-positive women or their networks have been invited only after agendas have been set or policy decisions taken, placing them in the role of reaction, disappointment and complaint rather than in a position of proactive, constructive and creative contribution. Moreover, women are invited to speak to ‘women’s issues’ only and are rarely asked to address broader

policy directives under consideration. Participation is seen as a privilege, rather than as a right, as meaningful, sustained engagement. HIV-positive women leaders from Latin America have therefore boldly embraced the position of *“nothing for us without us”*.

There is no consistent monitoring of involvement by key stakeholders in the AIDS response, and the deeper question of meaningful participation by those most affected by the epidemic is even more difficult to assess. However, after an extensive review of existing data, research and documentation along with lengthy in-depth interviews of key stakeholders in Southern Africa, South Asia, Southeast Asia, Latin America and elsewhere, the evidence is clear. Although women are on the frontlines pioneering initiatives that are central to the success of the AIDS response, they are not yet full participants in all levels of the response.

For example, critical stakeholders and representatives such as HIV-positive women, community-based care-givers or women’s rights advocates are largely absent from powerful agenda-setting mechanisms such as the AIDS coordinating authorities that dictate national AIDS policies or the Country Coordinating Mechanisms (CCMs) of the Global Fund to Fight AIDS, Tuberculosis and Malaria that largely control Global Fund processes and access to its resources at the national level. Further, women’s participation does not necessarily imply participation by or the representation of networks of women living with HIV, women’s rights organizations or grassroots women’s groups. So, even when gender parity is met, critical stakeholder involvement may not be.

Respondents consistently reported that even when women do hold a ‘seat at the table’ – whether it be in formal decision-making forums such as the CCM or at a meeting of NGOs – their presence is frequently contested or their expertise is looked to as only relevant to ‘women’s issues’ instead of as having a critical role to play as both speaking to issues of particular importance to women and

“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?”

— Beri Hull, ICW Global

informing discussion around HIV and AIDS policy and agenda setting in general.

*“Challenges faced by women in Namibia are that they are rarely involved in policy-making unless it is specifically on women’s issues. When involved, their work often goes unrecognized and they have difficulty gaining access to or being taken seriously by policy makers. ... [the] involvement of positive women at country level CCM has been very difficult to secure any representation of women to get their voices heard and their concerns addressed.”<sup>16</sup>*

This perception of women’s limited ‘expertise’ not only denies women’s right to participate, but also perpetuates a gendered understanding of ‘expertise’ and involvement that fails to incorporate women’s realities and needs in policy and programme responses.

At the opening of the International Women’s Summit in Nairobi, Kenya, in July 2007, 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?

### **Challenges to women’s full involvement and meaningful participation**

Even as women actively strive to lead or even participate in civil society or governmental structures, significant barriers limit their capacity and reach. Interviews with key informants cited gender norms,

“I call upon women of the world to stand up and fight against violence and the spread of HIV and AIDS. Let’s not be bound by our cultures, which can be changed. Only we have the power to change our lives and our cultures.”

— Anita Isaacs, YWCA of Namibia, International Women’s Summit, 2007

## **BOX**

### **3**

## **Analysis from a sample of key informant interviews**

*with women leaders in Southeast Asia, East Africa, West Africa, Southern Africa and North America*

The main barriers to women’s leadership and participation in the AIDS response cited by women interviewed were:

- Cultural factors including gender norms – 79%
- The stigma of HIV and AIDS – 58%
- Lack of access to resources and economic disempowerment – 58%
- Lack of access to information and knowledge – 46%
- The burden of care-giving and women’s multiple responsibilities in the home – 46%
- Illiteracy – 46%
- Lack of self-esteem – 25%

Informants reported that these barriers were manifested as women’s exclusion from decision-making, women’s lack of voice, poor information dissemination to affected communities, abandonment and divorce for women living with HIV, and inadequate funding to implement programmes or access to resources to support advocacy.

Informants all agreed that support for women’s mobilization, including investment in capacity building and funding for networks for women living with HIV, is a key strategy to overcome these barriers.

“Many women are conducting their HIV activism in a totally voluntary capacity. There are thousands of positive women around the world who may wish to be activists. Yet, they have no financial backing whatsoever, no moral support from their partners, and no computer, phone, Internet access, credit card or time. Many local and national organisations of HIV-positive activists are run by volunteers, who are largely women, but are staffed and governed largely by men in the paid posts, who then have access to desk space, computers, phones, vehicles, Internet, paid time to think rather than just do, to travel to, and take part in meetings. These men are therefore also involved in agenda setting and acquire status in these roles.”

— Alice Welbourn, Founder of the Salamander Trust, Creator of Stepping Stones, and former Chair of ICW

stigma, lack of access to resources and information, the burden of care-giving, illiteracy and low self-esteem as central barriers to the full involvement and meaningful participation of women, particularly of those most affected by HIV and AIDS (see Box 3). Other obstacles consistently mentioned, although with less frequency, included gender-based violence and a lack of access to health care.

The following sub-sections explore how these forces play out and interact.

#### ► **Stigma, discrimination and violence**

Women face stigma and discrimination as they are blamed as vectors of disease in their homes and communities.

*“In households that are affected, everything is blamed on the women.”<sup>17</sup>*

Further, available research has shown that women’s active participation in HIV advocacy or in positive women’s networks is linked to a perception of them as living with HIV or to disclosure of their HIV-positive status. This, in turn, can lead to stigma and violence from family and community. This fear of stigma and discrimination from living publicly with HIV was frequently cited as a central barrier to the full and meaningful involvement of HIV-positive women.

#### ► **Burden of care and multiple responsibilities**

Women shoulder the responsibility for running their homes and caring for their families.

*“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.”<sup>18</sup>*

Women’s responsibilities within their homes also limit their ability to travel for extended lengths of time to attend or participate in meetings or trainings.

Moreover, the multiple roles women undertake in the context of HIV and AIDS,

including care-giving, are neither recognized as a core component of the response nor compensated as work.

*“...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.”<sup>19</sup>*

#### ► **Gender inequality in decision-making and access to resources**

In addition to the limitations placed on women as a result of socially defined gender roles, women face further obstacles when attempting to engage with the AIDS movement as a whole, such as access to resources or ‘seats at the table’.

*“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.”<sup>20</sup>*

Investment in building the strategic capacity of the most affected women has been uneven. Women’s limited participation in strategic decision-making around funding and programmatic HIV and AIDS priorities has resulted in projects and programmes that too frequently focused on women as recipients of services rather than as agents of change.

Funding is frequently limited to discrete services – a workshop series or training, for example – and is not available for building the institutional capacity and infrastructure necessary for sustained work, networks or innovation.<sup>21</sup>

*“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.*<sup>22</sup>

Funding priorities are often donor-driven, and donor agencies do not always pay adequate attention to the extent to which allocated resources affect gender inequalities within organizational structures. As a result, these structures can perpetuate rather than transform existing gender imbalances in leadership and decision-making.<sup>23</sup>

*“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.”<sup>24</sup>*

#### ► **Lack of transparent entry points and capacity to participate**

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 [National Institutes of Health]? ... 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?”<sup>25</sup>*

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. This is another example of how women are often excluded due to their realities. Low levels of literacy and formal education also make participation a challenge.<sup>26</sup> These structural barriers do not only have an impact on the representation of critical stakeholders in communication and decision-making processes, but

also limit the extent to which the realities and needs of women – as expressed and voiced by women, particularly those most affected – are taken into account.

#### ► **Absence of critical alliances**

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, although the degree of alliances and joint action varies depending on the sites and regions.<sup>27</sup>

There are frequent divides between the particular experience of grassroots women or home-based care-givers and the advocacy of women’s rights actors. The mainstream agenda of women’s rights activists has tended to marginalize the participation of specific groups of women, including Indigenous and migrant women as well as women in prison. Sex work 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 in the context of HIV and AIDS, this issue is not consistently on the women and HIV agenda. Women who use drugs also struggle to add a gender perspective to harm reduction policies and programmes. The expertise of the disability rights’ movement and the compounded vulnerability to and from HIV that disabled women face is not as central a thread of the response to women and AIDS as it should be. The manner in which young women struggle to have a voice and be recognized in the women’s sector is another case in point.

Further, as noted by many informants, there is also the ongoing challenge for positive women’s organizations to be fully recognized and supported by women’s organizations and the women’s movement. The lack of integration between and among overlapping and related movements suggests the need for establishing stronger horizontal alliances.

“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.”

— ICW Brazil

IS THIS  
SCALING  
UP ???

## Chapter 3

# Women's Involvement in the National AIDS Response: Case Studies

**H**ow has women's right to participate been realized at the country level? What is the current status of women's participation in the AIDS response, particularly with respect to formal and informal decision-making structures? What does women's full and meaningful involvement in the AIDS response mean at the country level and how does it work?

This chapter features five case studies exploring different aspects of the questions raised above and bringing to the review complementary, yet distinct, analyses. It includes three different country examples – Brazil, India and South Africa – as well as a snapshot of the Global Fund's Country Coordinating Mechanisms (CCMs) and a look at efforts to promote HIV-positive women's leadership in monitoring progress and holding policy-makers accountable to commitments using community-based monitoring and evaluation approaches. The case studies have been developed to illustrate at a practical and experiential level what women's involvement in the AIDS response looks like at the national level.

### Case Study 1

#### South Africa: Political leadership and the implications for women's participation in the AIDS response<sup>28</sup>

##### The context of HIV and AIDS in South Africa

Political leadership is widely recognized as a key element of an effective national response to HIV and AIDS. Until very

recently, the failure of South Africa's leadership to respond appropriately to the epidemic was often a focus of debate and criticism. However, changes in the country's political leadership in 2009 brought with it changes to the national response to HIV and AIDS as well as a renewed commitment to the timely implementation of the National Strategic Plan (NSP) for STIs and HIV and AIDS 2007–2011. The new Cabinet also introduced a number of policy changes, most notably in the context of HIV testing and treatment, including access to programmes for the prevention of vertical transmission of HIV.

It is also important to recognize that activists have been at the forefront of leading changes in policy and treatment availability in South Africa. For example, they have succeeded in making prevention of mother-to-child transmission (PMTCT) services available, introducing changes in drug and therapy regimens and developing and/or adapting national HIV and AID policies to address realities and challenges. The most notable achievement of civil society has been the widely referenced Treatment Action Campaign (TAC) court action against the Minister of Health for the failure to provide Nevirapine and PMTCT programmes, which subsequently lead to a Constitutional Court ruling ordering the Health Ministry to afford all pregnant women access to the latter.<sup>29</sup>

Despite these recent achievements, numerous challenges remain that undermine the adequacy of the national response as well as the extent to which women's leadership and participation is meaningful. Examples of these challenges include the slow responses in rolling out

"A network of positive women would become a force on their own. They would have strength on their own. They would be able to know, as women, there are areas where they can come in, in the national response. We are living in a blind daze and we just sit. What we are asked to do, we do because we lack capacity for these strategic meetings. People are just there at the top and they don't speak for the voices of these women. If the capacity is there, you have a voice. With capacity, you can move into advocacy where you know what to say, what to ask for."

— *Esse Nsed, Positive Development Foundation, Nigeria*

HIV treatment and changing drug regimens according to new research findings; the inadequate implementation of new treatment guidelines affording women greater access; the persistent failure to adequately focus on successful and women-centred HIV prevention efforts; and the continued inflammatory statements by political leaders about women, sex and HIV prevention.

The need for critical engagement between civil society and the Government on all issues affecting the national AIDS response remains pressing. This is to ensure that the effectiveness of available programmes and services is an ongoing

process and to ensure responsiveness to women's realities, needs, risks and vulnerabilities. One of the main areas in which this process unfolds is, undoubtedly, the South African National AIDS Council (SANAC), as the various structures within SANAC have strong civil society representation, providing the opportunity for discourse and engagement between civil society and the Government on a wide range of issues, including policy reform processes. Civil society also plays a vital role in enhancing communities' capacity to actively engage various stakeholders on the issues affecting their lives, including the adequate and rights-protecting delivery of HIV testing, prevention, treatment, care and support services.

### Promising Approaches

## Knowledge is power

### The Well Project

Developed by and administered with women living with HIV, The Well Project in the United States provides a model for how research, policy and practice can be translated into terms that can be used by women living with HIV and their caregivers and health providers. The Well Project is changing the course of HIV and AIDS through its provision of up-to-date research and educational resources on women and HIV.

### The Women's Collective of the United States

The Women's Collective, a non-profit organization in Washington, DC, provides a model of how organizations led by and with women living with HIV can successfully reach those women and their families by providing holistic services that are peer-based, woman-focused, family-centred and culturally appropriate. *"Our policy and advocacy team is in the privileged position of being in an office that has direct contact with women living with HIV/AIDS and their families. We see the everyday effects of these policies. For us, policies are more than documents and ideas but living and breathing realities. When a program is cut or is successful, we all experience the impact firsthand."*

### Women's participation and leadership in the formal AIDS response

During the consultative processes leading to the development and approval of the NSP at the end of 2006, various women's and human rights groups and activists voiced strong concerns that the draft document did not adequately reflect or respond to the situation of women. To address this gap, a number of women's advocates and rights activists from different sectors came together in March 2007 for the 1st SANAC Women's Sector Summit, developing a revised draft that was inclusive of and responsive to women's realities, needs and risks. The final version of the NSP, which was adopted by Cabinet in May 2007, included many of the recommendations made during this Summit.

Although some questioned its representativeness, the Summit was an important event for women's participation and leadership in the formal AIDS response. It brought about an ad-hoc and direct advocacy response by numerous women and women's rights organizations who actively participated in the drafting of the national AIDS policy, and took leadership so as to ensure that women's voices and concerns were heard and included in the policy framework. Since then, the SANAC Women's Sector has led and supported

a number of initiatives, emphasizing specifically the extent to which policies, programmes and initiatives address the realities and needs of women, as well as questioning the adequacy of the national AIDS response in this regard. An HIV prevention summit, a consultation on the roll-out of medical male circumcision and its impact on women, as well as a consultative workshop on sex workers' rights and FIFAs<sup>30</sup> are a few of the activities led and supported since 2008.

Strong women leaders are found at all levels of SANAC structures, ranging from the high plenary and programme implementation committee to the 17 civil society sectors that are represented. This is arguably a clear indication that mechanisms facilitating women's involvement, participation and leadership are in place. However, questions have to be raised as to their meaningful participation as well as the 'real' impact of their representation in these structures as this does not necessarily translate into strong representation of women's needs and realities.

### Remaining challenges

While recognizing the many strides that have been made towards women's participation and leadership in the formal AIDS response, it is important to acknowledge that there are still a number of challenges remaining. 'Gender representation' in decision-making structures is of great importance, but women elected into these structures must also be in a position and have the capacity to negotiate and facilitate decision-making processes that are based on and responsive to women's rights, realities, needs and concerns. In addition, key to achieving women's effective and meaningful participation and leadership in all aspects of the AIDS response is ensuring that the 'right women sit at the table'<sup>31</sup> of decision-making processes of the AIDS response.

It is also of critical importance to ensure the participation and leadership of HIV-positive women. There seems to be a lack of mechanisms and political will to facilitate and ensure not only their

representation in the various SANAC structures, but also their meaningful participation and leadership, as compared to 'tokenism' and 'gender representation' without the necessary enabling environment to adequately hear their voices and address their concerns. And while this challenge may not be unique to the South African context, it greatly affects the extent to which specific needs, realities and risks of women living with HIV are taken into account and addressed by the national response.

One SANAC representative living with HIV commented on her role in formal response mechanisms that she had just thought she had to be on the committee as an HIV-positive person, but had "*never thought of raising her own issues or having the confidence to do so*". Statements like this clearly underscore challenges in relation to both positive women's representation as such and the necessary capacity and consciousness to represent voices, and advocate for the specific realities and needs of positive women.

Many HIV and AIDS interventions and programmes still fail to respond to women's needs and realities and therefore fail to significantly reduce women's risk and vulnerabilities. While South Africa's legislative and policy framework is fundamentally based on equal rights for all, and prohibits any form of gender inequality, women's realities are not coinciding with these provisions and guarantees. There remains a consistent failure and reluctance to challenge and transform the patriarchal paradigm in which the national response to HIV and AIDS is designed, implemented and monitored. Thus, gendered realities, including unequal power relations and gendered concepts of sex and sexuality – all factors impacting on women's risks and vulnerabilities – are neither questioned nor challenged. Given the limited impact of any AIDS response that fails to transform the societal context defining women's vulnerabilities and risks, the efficacy of women's participation and leadership in the response to HIV and AIDS should be measured by the extent

to which women are in a position to challenge the patriarchal system and create an enabling environment for women's real participation and leadership.

## Case Study 2

### Brazil: The importance of social movements for the involvement of HIV-positive women<sup>32</sup>

The National AIDS Control Authority in Brazil is a Department of the Ministry of Health and is known as the Department of STD/AIDS and Viral Hepatitis. Brazil has a national Plan to Combat the Feminization of AIDS and other STDs that was launched in 2007; however, its implementation remains a major challenge, with no clear allocation of resources, difficulties in

promoting intersectoral action as required in the Plan, and large variations in the level of implementation in the different regions and states.

An analysis of AIDS cases by gender shows that the incidence rate among men in 2008 was 22.3 cases per 100,000 inhabitants, while the rate among women was 14.2 per 100,000. The highest incidence rates for both women and men are in the 25–49 age group and there is an increasing trend in the last 10 years among those over 40. The sex ratio (M:F) in Brazil has decreased considerably since the beginning of the epidemic: in 1986 the ratio was 15.1:1 while from 2002 it stabilized at 1.5:1. In the 13–19 age group, the number of AIDS cases has been higher among girls since 1998.<sup>33</sup>

### Participation of women living with HIV in formal and informal AIDS response mechanisms

The Department of STD/AIDS is currently coordinated by a woman (for the second time since it was created) but there are no formal regulations to promote or guarantee gender parity in its governance structure. It is important to point out, however, that the Department has several members of its team, women among them, who openly declare themselves as persons living with HIV. Most of them have come from social movements such as AIDS NGOs or networks. As there is no formal requirement for Department staff to identify their HIV status, it is difficult to determine the percentage their presence represents.

According to a survey carried out by civil society to monitor UNGASS/AIDS Declaration commitments concerning women's sexual and reproductive health,<sup>34</sup> and in particular the leadership and participation of women (including women living with HIV) in the spheres of decision-making on AIDS policies:

*"The Ministry of Health currently has a specific department for liaison with civil society, namely the Department of Strategic and Participative*

#### Promising Approaches

### Mobilize communities for change

#### Mama's Club of Uganda

The Mama's Club of Uganda is a peer education, advocacy and information resource for young HIV-positive mothers to gain psychosocial support, knowledge and training at the intersection of sexual and reproductive rights and health and HIV. Organized by and made up of women living with HIV, the Mama's Club is a model for community-based support, mobilization and change that can work to ensure the health and welfare of HIV-positive women and their families and communities. It has carried forward three key priorities to date: (1) male involvement in the prevention of perinatal transmission; (2) strides to positive parenthood; and (3) protect and support young mothers. The Mama's Club is a 2008 Red Ribbon Award recipient. Through mobilizing young mothers who are living with HIV, it has created an engine for advancing sexual and reproductive health and rights as well as for facilitating local women's participation in the AIDS response.

*Management. Furthermore, the structure of the National Health System<sup>35</sup> (NHS) provides for the equal participation of civil society on the National Health Council (NHC), which is the highest decision-making level of the NHS. It is a space where all national health policies are discussed before being approved for implementation. The seat allocated to people living with HIV on the NHC is among the seats reserved for organizations representing people living with diseases. The National Health Council also has an Intersectoral Commission on Women's Health where, although there is no specific representation of women living with HIV, they are nevertheless able (or should be) to put forward their demands. As such, formal channels of interlocution do exist between the government and civil society within the Ministry of Health as a whole. Thus, in terms of structure, the NHC is above the Department of STD/AIDS.*

*The Department of STD/AIDS is able to call upon the consultative input of the National AIDS Commission, created at the end of the 1980s. Civil society has 7 seats on this Commission, although the process of choosing participants does not ensure gender parity. The Department of STD/AIDS also has thematic advisory committees that have civil society representation. However, the women's advisory committee, created in 1995, was deactivated in 2003. In the same year the Commission for Articulation with Social Movements (CAMS) was created, on which social movements are also represented. This Commission has one seat for the women's movement,<sup>36</sup> one seat for the transsexual movement, and one for the National Network of People Living with HIV/AIDS-RNP+. This structure of representation is not repeated at state and municipal level, where civil society only takes part in Health Councils. However, none of these spaces provides for parity in the representation of men and women."<sup>37</sup>*

The Intersectoral Commission on Women's Health provides support to the Council in discussions regarding the monitoring of policies directed at women's health. There are no centralized data on the participation of women living with HIV on state and municipal Health Councils.

Regarding the numbers of women and their position in joint UN mechanisms, 5 of the 17 UN agencies with representation in Brazil are headed by women in 2010, all of whom are full members of the United Nations Country Team but none of whom is (at least openly) living with HIV.<sup>38</sup> In the UN Expanded Theme Group on HIV/AIDS (GT/UNAIDS), there is no specific seat for women living with HIV. Currently, the substitute representative of the National Network of People Living with HIV (RNP+) is a man.

### **Leadership of women living with HIV**

Although the RNP+ was formed in 1995, it was only at the end of the 1990s that

#### **Promising Approaches**

### **Involve grassroots women**

#### **Local to Local Dialogues of the Huairou Commission**

Local to Local Dialogues are locally designed strategies whereby grassroots women's groups initiate and engage in ongoing dialogues with local authorities to negotiate a range of development issues and priorities to influence policies, plans and programmes in ways that address women's priorities. Dialogues are convened by grassroots women and used to change the terms of negotiation between communities and local authorities. Successes achieved include opportunities in Rwanda for grassroots women to submit their HIV response plans to local authorities for formal integration into overall District plans. Lessons learned include the need for investment to ensure that the dialogues are an ongoing initiative rather than a one-time event.

issues concerning women living with AIDS began to be discussed in a more effective manner as a result of the mobilization of women advocates from NGOs involved in HIV prevention. In August 2004, the creation of the National Movement of Positive Women Citizens (MNCP) was formalized. According to its leadership, it currently has more than 200 participants. MNCP focuses on identifying solutions for better health, living and working conditions and education. According to its Charter of Principles:

*“The MNCP seeks to strengthen women living with HIV by establishing action strategies that will lead them to an acceptance of their HIV serum status and based on that, to occupy once*

*more their social positions and fully exercise their citizenship, combating isolation and inertia, fostering exchanges of information and experiences and improving their quality of life. A further principle of MNCP is to work for the prevention of HIV infection of non infected women in the country seeking to control the epidemic in Brazil.”<sup>39</sup>*

Among the major challenges the movement faces are questions related to its financial sustainability and politicizing and qualifying leaders. One MNCP participant states that, *“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.”* An RNP+ activist recognizes that there is still a long way to go, observing that, *“(…) in spite of their gaining strength increasingly, there are only specific places allotted for women living with HIV when places for participating in an event (meeting, seminar, workshop) come up for discussion. However, in formal terms, I do not know of any space for them (…).”* The National AIDS Movement in Brazil has helped to promote the leadership of women at the national level insofar as some NGO forums have places specifically allocated for women living with HIV.

The Government’s view<sup>40</sup> concerning the achievements of these women-led initiatives in the national response to AIDS is that, *“the very fact of setting up the MNCP has made it possible to expand the representation of HIV+ women in the spaces where policy discussions take place and to visualize the specificities of living with HIV/AIDS”* in regard to policies for women, women’s health and other needs. The organized social movement has also made it possible for women living with HIV to become agents of change in local, national and international spheres. The participation of women living with HIV in the spaces referred to *“(…) qualifies the responses, includes specificities and poses us the challenge of putting*

### Promising Approaches

## Bring forward young women leaders

### Namibia Women’s Health Network

The Namibia Women’s Health Network is the first network of HIV-positive women, founded with a majority of young women. It builds on the alliances built through the Parliamentarians for Women’s Health project with policy-makers (Members of Parliament sitting in the Parliamentary Standing Committee on Human Resources, Social and Community Development), civil society and community-based organizations, faith-based entities and the private sector. Additionally, the Ministries of Health and Social Services and Gender Equality and Child Welfare, as well as the Southern African Development Community (SADC) Parliamentary Forum and the UN family in Namibia are key allies. Through the Young Women’s Dialogue – led by the Namibia Women’s Health Network and ICW Namibia to mobilize and create space for HIV-positive young women – one of the young women participants has been nominated by the National Council at Parliament to sit in its HIV and AIDS committee.

into effect the integral aspect of health".<sup>41</sup> However, the existence of the MNCP does not mean that women living with AIDS are in fact participating at all levels in decisions regarding AIDS policies in Brazil.

### **A path forward: reflecting on the need to link social movements**

There is a need to foster greater integration of the agendas of the feminist movement and the AIDS movement that seeks to prevent the spread of new infections among women as well as strengthen HIV-positive women who have been fighting to guarantee their human rights, including their sexual and reproductive rights. In spite of AIDS being on the increase among women, especially in the poorer regions of Brazil where economic conditions and gender relations are more unequal,

*"until 2007 there was a reduced number of NGOs working with HIV/AIDS prevention among women and young people due the cuts in financing for sexual and reproductive health projects and prioritizing of other themes, especially violence and abortion, on the agenda of the feminist movement."*<sup>42</sup>

Starting in 2007, however, a few AIDS organizations began to collaborate more directly with the women's movement in an effort to strengthen understanding of the interface between violence against women and AIDS. In addition, more emphasis and research has been given to the discussion on sexual and reproductive health and AIDS. This was the main theme of the VI Forum UNGASS-AIDS, coordinated by the NGOs Gestos and GAPA-SP and held in May 2010. The event brought together the heads of the Department of STD/AIDS, UNAIDS and about 60 leaders of the AIDS movement, including women living with AIDS and lesbians, gays, bisexuals and transvestites (LGBT).

Yet, the integration of public policies with women and AIDS policies remains a challenge for the Government given the limited presence of women living with HIV in such spaces. For example, the 2007

## **Promising Approaches**

### **Engender the national AIDS response**

#### **National Strategic Framework for HIV/AIDS of Nigeria**

Nigeria provides a successful template for how the relationship between gender and HIV, particularly for women and girls, can be addressed through national response mechanisms. UNIFEM, together with a consortium of partners including the Canadian International Development Agency (CIDA), successfully supported the engendering of the National Strategic Framework for HIV/AIDS (2005–2009) through a multi-dimensional approach using the following key strategies:

- 1) Creation of a Gender Technical Committee comprised of UN entities, bilateral agencies, civil society organizations focused on women and HIV, governmental agencies and ministries, among others, in the National Agency for the Control of AIDS (NACA);
- 2) Advocacy for the establishment of a core thematic focus area on gender;
- 3) Provision of gender technical support, including involvement of gender experts and champions for ongoing consultation and input, for the NACA;
- 4) Engagement of all key stakeholders through regular briefings and updates so that the work of the gender experts can be consistently validated;
- 5) Advocacy and training with members of the State Action Committees on AIDS and other stakeholders at the state level to incorporate gender equality aspects of the National Strategic Framework; and
- 6) Documentation of the process for replication in other settings.

## Promising Approaches

### **Build coalitions and alliances amongst key groups to facilitate greater coherence**

#### **Coalition of First Ladies and Women Leaders of Latin America on HIV**

Former First Lady Xiomara Castro de Zelaya of Honduras initiated the Coalition in 2006 in order to promote political commitment; increase the mobilization of regional and national resources to enhance prevention, treatment and care services; and reduce the impact of the epidemic on women and girls.<sup>73</sup> Its continued growth and success can be attributed to its bringing together of a diverse cadre of women leaders and, in particular, to its recognition of the pivotal role women living with HIV have in leading the response to the epidemic. One result of this alliance building can be seen in the nomination of Patricia Perez of Argentina, regional coordinator for ICW Latina, for the Nobel Peace Prize.<sup>74</sup> Patricia is the first HIV-positive woman to be given such an honour.

#### **Women WON'T Wait Coalition**

The Women WON'T Wait Coalition includes women's organizations from the South and North who work at the intersection of women's human rights and violence against women. Adopting a feminist agenda and with a small core group of partners, the architects of the coalition decided against a 'big tent' approach, according to coordinator Neelanjana Mukhia.<sup>75</sup> The accountability focus and the successful launch of, 'Show Us the Money: Is Violence Against Women on the HIV&AIDS Donor Agenda?', has brought a groundswell in donor attention to addressing violence against women as a core response to HIV and AIDS and to putting the necessary line items in budgets to move forward. The Coalition has also developed toolkits of indicators and targets that women's organizations at the national level can use to hold donors and their governments to account.

Plan to Combat the Feminization of AIDS and other STDs was intended to be executed in partnership between the Department of STD/AIDS and the Technical Area of Women's Health. The state's plans for making the plan known and discussing the process for making it operational at a local level with local managers was only recently completed. It is thus too early to reflect on the level of civil society participation in this process but in many states – for example, Pernambuco – such participation was the result of civil society pressure. Difficulties were identified during the process of constructing the proposal, which failed to meaningfully involve the MNCP leadership in designing it, and there are very few actions in the AIDS movement or in the HIV-positive women's movement that make full use of the knowledge and expertise MNCP has to offer. This is particularly the case because many of the Plan's proposed activities have to be put into effect by the Services Units, which still have great difficulty in handling the specificities of HIV-positive women.

To support the strengthening of positive women citizens' participation, it is important to analyse the political scenario, the present situation of the AIDS, health, human rights and women's rights movements and, in a more collective and integrated manner, come to an understanding of the challenges these movements face. This is all the more vital because the Policy for Integral Health Care for Women clearly indicates that it is indispensable to bring these women into the discussion of everything that has to do with access to services and their participation in the process of constructing, accompanying and implementing the policies. This does not actually take place in the same way in all the states or in all the spheres of discussions on AIDS. *"In practice, it takes place to a greater or lesser extent depending on the local administrator"*,<sup>44</sup> which means that there is an urgent need for a more integrated and interactive presence of positive women citizens in every one of the Brazilian states.

"When women are made to lead in the fight against HIV/AIDS in each local government area, the battle against the virus would be won."

— Professor Babatunde Osotimehin, Director of the National Agency for the Control of AIDS, Nigeria

## Case Study 3

### India: strengths and achievements of the Positive Women's Network<sup>45</sup>

#### Exploring positive women's leadership in the AIDS response in India

India's story shows women living with HIV taking centre stage in discussions and policy formulations, providing crucial links based on their personal experiences and mobilizing to shape the AIDS response. The journey of women living with HIV from invisibility to the forefront of campaigns and activism is one of empowerment and pioneering leadership. Yet, even as women living with HIV have mobilized and have been extremely effective in influencing the AIDS response in India, they are still absent from formal structures such as the Global Fund's CCM.

Personal narratives and testimonies of HIV-positive women are aligned with broader issues of women's exclusion, subordination and exploitation. In mobilizing and exploring their own marginalization, HIV-positive women in India broke many barriers and understood their own collective strength. They have spoken up in every forum and have made clear a quiet assertion that there was nothing to lose and everything to gain. Further, the Positive Women's Network (PWN+) has fearlessly engaged with difficult issues such as law reform and property rights. Women's right advocate Akhila Sivasdas from the Centre for Action Research views these HIV-positive women leaders as the cutting edge of policies and programmes that reach the heart of women's rights in the country.<sup>46</sup>

The strength of PWN+ is that it has emerged from collective processes and has had an autonomous existence so that while strong partnerships with state, United Nations and civil society actors have been established, it has had the independence to give voice and visibility to the realities HIV-positive women face

and to transform the personal into the political through mobilizing HIV-positive women as agents of change and leaders in both the formal and informal AIDS response.

An all-women group, PWN+ was formed in 1998 by 18 members predominantly from the state of Tamil Nadu who sought a support system and wanted to improve their quality of life and that of their children.

*"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."<sup>47</sup>*

A unified vision document of PWN+ evolved from a process of regional workshops in the North (New Delhi), North East (Guwahati) and South (Chennai) in 2002–2003 that was supported by UNIFEM. National Consultations (2002 and 2004) helped refine their programmes and facilitated the submission of recommendations to the Government enabling network members to arrive at strategic goals, spell out core objectives and agree on practical strategies and activities. PWN+ set the following objectives:

- *"At PWN+, we see ignorance and harmful attitudes as our greatest enemies, not HIV/AIDS. Therefore, our foremost objective is to create an enabling environment for women living with HIV/AIDS by destigmatizing HIV/AIDS."*
- *"Women and their families suffer because they do not have the right kind of knowledge about HIV/AIDS issues. Another major objective therefore is to educate women living with HIV/AIDS and their families in order to increase their awareness of issues that affect them."*

"In the many years advocating around sexual and reproductive matters, we didn't succeed as effectively as when HIV-positive women advocate."

— Akhila Sivasdas,  
Centre for Action  
Research, India

- *“Women need to know what the support services are that they can access and then select the path to better lives. Another equally important objective, therefore, is to establish a system of referral services.”*  
*“In addition to these, we seek to empower women living with HIV/AIDS.”*

PWN+ has partnered with the National AIDS Control Organisation (NACO), the National Commission for Women, the Tamil Nadu State AIDS Control Society, UNIFEM, UNAIDS, UNDP and the Indian network for people living with HIV/AIDS (INP+), among many others.

*“The Positive Women’s Network has translated personal experiences into policy statements. ... Their modus operandi has been to impact policy in a strategic and focused manner.”<sup>48</sup>*

Today, they assert their agency, demand their space and rights and, broadly, define India’s gendered response to HIV and AIDS. PWN+ has continued to expand its network to more states, boasting a membership of over 6,000 women and implementing projects supported by the state and national government offices as well as various UN and other international agencies.

UNIFEM has played a core supporting role in the journey of PWN+ since 2000 by mentoring the advocacy and alliance-building processes, linking the issues of positive women’s participation, access and decision-making to the regional, national and international levels with a wide spectrum of actors from women’s rights groups, gender advocates and multilateral organizations.

### **What are the obstacles positive women have faced?**

Even in light of the tremendous success PWN+ has had in mobilizing and supporting women living with HIV, and translating the personal to the political, persistent challenges remain. Some of these, which echo reports from HIV-positive

women from many different countries, include:<sup>49</sup>

- Inadequate support is provided to and funding for positive women-led organizations and programmes;
- Women living with HIV are nominated in a tokenistic way even in common networks of people living with HIV and AIDS;
- HIV-positive women are continually under-represented in formal decision-making forums;
- Women living with HIV who are represented on various governmental and non-governmental committees frequently lack adequate knowledge or gender expertise; and,
- There is a need to care for children and families.

### **Parameters for success**

Acknowledging the strength of community leadership – and bringing that leadership into formal mechanisms through support, investment and meaningful partnerships – is a fundamental component of building an effective HIV and AIDS response that is accountable and responsive to the realities on the ground.

*“There is no way to approach realities at the most local level without support from the ground up. ... Teaching sites and models exist in local communities. There is no need to reinvent the wheel. The process of transformation can be taught. ... The community-led advocacy model of the Positive Women’s Network has left a legacy of deep learning for other community groups.”<sup>50</sup>*

The success of PWN+ is that it influences and shapes mainstream and micro level processes, and demonstrates the power of inserting a persistent voice and presence at all levels of decision-making in the AIDS response. PWN+ has identified six essential parameters for the successful leadership and participation of HIV-positive women in the AIDS response:

- HIV-positive women can voice their opinion and concerns only if there are networks, for and by women living with HIV at all levels;
- Women living with HIV should be involved and represented in all governmental and other organizations responding to HIV and AIDS;
- Women living with HIV should be involved in both the planning and implementation phases of policies and programmes;
- Sustained investment in grassroots programmes is central to the development and engagement in the AIDS response of those most affected;
- Annual GIPA (greater involvement of people living with HIV/AIDS) audits are needed on the involvement of women living with HIV across all sectors of the AIDS response; and,
- Advocacy opportunities should be provided for HIV-positive women at the district, state and national level.

## Case Study 4

### Resource mobilization and accessing the Global Fund to Fight AIDS, Tuberculosis and Malaria: where are women?

*“Women need to become more involved in Country Coordination Mechanisms [CCM] of the Global Fund ... and the global community has a responsibility to ensure that we build the capacity of these stakeholders so that they can sit on the CCM in a pro-active way.”*

—Violeta Ross, Former LAC Region Delegate, NGO Delegation of the Global Fund Board

In a 2008 report entitled “Do Global Fund Grants Work for Women?” that reviewed 211 proposals from 39 sub-Saharan African countries submitted and approved during Rounds 1-7,<sup>51</sup> Aidspan concluded that the Global Fund was “only partially” addressing women’s meaningful

participation and gender inequality issues in its structures and processes as well as in its programming.<sup>52</sup> In that same year, the Global Fund issued a Gender Equality Strategy aimed at strengthening and scaling up its investments in more gender-sensitive responses to the three diseases that called, inter alia, for achieving a gender balance and integrating gender expertise in the policies, procedures and structures of the Global Fund as well as strengthening partnerships that support programmes to address gender inequalities and reduce women’s and girls’ vulnerabilities.

#### Promising Approaches

### Tap the power of women’s voices

#### DIAMONDS: Stories of Women from the Asia Pacific Network of People Living with HIV

The personal is political. Women speaking in their own voice about their own lived experience holds tremendous potential for shaping change whether it be empowerment; eliminating isolation, fear and stigma; or advancing research, policies and programmes that resonate with on-the-ground realities. This is illustrated by the following extract from Frika’s personal account in DIAMONDS, a compilation of stories about the lives of women living with HIV in the Asia-Pacific region.

*“During that year in rehab, I was trained in counselling, public speaking and how to facilitate sessions. This was the foundation for me running trainings now. I started to speak out in schools and seminars. Not just about my HIV status, but also about my journey from being an addict. I felt it was a relief to share my experience in public and be open. It also felt good to be educating people. I’d been feeling useless for so long, only thinking about me, me, me and how to get my drugs each day. This training made me feel that I could use my experience in a positive way to help other people.”<sup>76</sup>*

“Meetings are often very formal, where people can’t even see each other round the long thin table, let alone make eye contact, view body language or even hear properly what others are saying. There is a need for policy-makers to learn about how to work in different, more equitable ways. . . Positive women who are due to attend formal meetings need mentoring support from other positive women who are already used to these traditional ways of working, and who feel less daunted and alienated by these traditional hierarchical structures. Otherwise, meeting styles can be very intimidating and off-putting for newer or younger delegates, especially if they are not totally at home in reading, speaking, and understanding the language in which the meeting is held.”

— Alice Welbourn, Founder of the Salamander Trust, Creator of Stepping Stones, and former Chair of ICW

While modest progress has been made in increasing the number of women in the Global Fund’s governance structures and operational mechanisms, gender imbalances persist. For example, only 4 of the 20 voting members of its Board – which holds broad oversight and sets policies – are women; one of them serves as the NGO representative for communities living with and affected by the diseases and none of them identify as living with HIV. With only 20 per cent of its members being women, the Board falls short of meeting a standard of gender parity considering the feminization and disproportionate impact of the three diseases on women worldwide. Within the Global Fund’s Secretariat, women constitute 60 per cent of the staff; however, they hold only 29 per cent of management and/or decision-making positions.<sup>53</sup> To strengthen its internal capacity on gender, the Global Fund has recruited a senior-level Gender Advisor (“Gender Champion”) to develop a detailed implementation plan to accompany the Gender Equality Strategy. Investment is planned in mandatory, ongoing, institution-wide specialized training for key personnel in management and leadership positions.

One area that has seen marked improvement with respect to gender balance is membership of the Technical Review Panel (TRP). In Round 9, the TRP expanded its membership from 35 to 40 experts where women constituted 45 per cent of TRP members, a slight increase over Round 8 and a dramatic improvement from 29 per cent in Round 7. Moreover, 3 of the 12 new members were recruited on the basis of their cross-cutting expertise with a focus on gender and sexual minorities.<sup>54</sup>

At national levels, the number of women represented on CCMs – multi-stakeholder platforms that serve as strategic entry points for women and civil society organizations – hovers around 34 per cent globally. Regionally, the proportion of women varies from a low of 17.8 per cent in South and West Asia to a high of 45 per cent in Latin America and the Caribbean.<sup>55</sup> Of the Chairs and Vice Chairs of CCMs,

the proportion of women is 20 per cent and 25 per cent respectively.<sup>56</sup> The global participation rate of People Living with the Disease (PLWD) on CCMs is 8 per cent and 1 per cent for Key Affected Populations.<sup>57</sup> Despite being a condition of funding eligibility, the representation of these vulnerable groups on CCMs remains minimal and has shown little improvement over time.<sup>58</sup> In addition, what the data do not reflect are the actual roles of the different constituencies on CCMs or the nature and degree of their involvement in CCM processes. As David Winters, Global Fund CCMs Manager commented, “Many missed the first few years of the Global Fund and the opportunity to shape the [CCM] from the ground up.”<sup>59</sup>

In an effort to align its CCM structure and processes with the Global Fund’s guiding principles of broad representation and gender balance, India invited the Ministry for Women and Child Development as well as the Indian Network of Positive People (INP+) to be regular members on the CCM. In addition, the CCM in India has established a new gender seat, and its Secretariat is currently headed and supported by women. However, no woman who has identified herself as living with HIV sits or is formally represented. To ensure the integration of gender issues in programming, the CCM in India solicited the active inclusion and participation of UNIFEM and other women’s agencies and organizations in the deliberations for the development of proposals for Round 9.

Women, particularly those most affected by the epidemic, still face challenges in their efforts to access resources from the Global Fund and to participate in CCMs. Jennifer Gatsi of the Namibia Women’s Health Network reports that, “women don’t have the information on how to sit in those positions”. Even when women living with HIV do hold a seat on the CCM, negotiating the complex political terrain of the structure makes it difficult to have a voice in decision-making.<sup>60</sup> Moreover, much of the work of the CCM occurs at retreats for which representatives from

affected communities might have limited resources to participate.<sup>61</sup>

In 2009, the Global Fund launched a partnership e-forum on gender to engage a broader constituency of stakeholders. Simultaneously, key civil society leaders introduced new initiatives to support the engagement of women's coalitions in proposal development efforts in Southern African countries;<sup>62</sup> to strengthen the linkages between sexual and reproductive health and HIV in programming;<sup>63</sup> and to recommend elements of gender transformative strategies for consideration by the Global Fund.<sup>64</sup>

The experience of the Swaziland Women and Girls' Coalition, which was formed in March 2007 to ensure participa-

tory and meaningful engagement of women and girls in the development of the country's Round 7 proposal to the Global Fund, underscores some of the challenges that stakeholders face in organizing and mobilizing a response. First, genuine consultation and engagement require resources and time, especially when diverse and broad-based constituencies are involved. Given the relatively brief turn-around time between the launch of a funding round by the Global Fund and proposal due dates, groups have to mobilize quickly and have ready access to funds to undertake consultative and participatory processes. Second, the significant technical skills needed to develop a proposal often exceed the

## BOX

### 4

## "If you're not at the table, you're on the menu"

*"The HIV epidemic in the United States has changed dramatically since the first cases of AIDS were identified among gay men in the 1980s. According to 2006 estimates by the Centers for Disease Control and Prevention (CDC), there are nearly 300,000 women living with HIV in the United States, not including transgender women, for whom no accurate data are available. Over the last 30 years, the epidemic's toll on women has steadily worsened and now appears to have stalled at a stubbornly high level. In 1985, the earliest year for which data are available, women represented 8 per cent of HIV infections. By 2006 this had more than tripled to 27 per cent. The epidemic is taking a particular toll on low-income women and women of colour, who make up 80 per cent of women living with HIV. Women living with and at risk for contracting HIV report disproportionate rates of violence, including both physical and sexual abuse. Women with HIV also tend to experience barriers to*

*HIV testing and worse health outcomes overall than men with HIV.*

*"During the summer of 2010 the United States will release its first ever National HIV/AIDS Strategy (NHAS). Many policies and programmes for HIV service delivery were crafted at a time when the demographics of the epidemic – and consequently the needs of those affected – looked very different than they do today. To reduce the rate of new HIV infections among women, and to increase access to care and utilization of treatment and support services, it is critical that HIV-positive women have a meaningful role in the design, implementation, monitoring and evaluation of the NHAS and the domestic HIV response overall. As they say, 'if you're not at the table, you're on the menu'. Civil society involvement should promote and secure HIV-positive women's leadership that is reflective of the epidemic."*

— Naina Khanna, Coordinator of the U.S. Positive Women's Network

capacity of grassroots organizations. Resources for hiring a technical expert to prepare a proposal should be given consideration. Even when a strong proposal is developed to reflect the priorities of women and girls who are affected by the epidemic, women's groups need to be able to navigate complex political processes. Significant negotiation and alliance building with members of the CCM are needed to ensure that the substance of the proposal is taken up into the official submission to the Global Fund.<sup>65</sup>

Similar lessons were obtained from Zimbabwe's experience in Round 7. The Working Group on Women, Girls and HIV/AIDS – a coalition bringing together various women's rights NGOs from across the country and supported by the Open Society Initiative for Southern Africa (OSISA) – faced a set of organizational, technical and political challenges. At the organizational level, issues over coordination and communication as well as challenges with leadership delayed the proposal development process. Consultants were also found to be critical for the process, especially those with technical expertise on areas such as proposal writing, processes and budgeting as well as specific to the disease. The inadequate amount of time to prepare the proposal made it difficult for consultants and team leaders to obtain key inputs from members on the kinds of activities that would be carried out under the project and therefore prepare meaningful budgets. To enlist stronger support of other stakeholders, the Working Group will need to intensify its advocacy and lobbying between and among civil society, the CCM, UNAIDS and other stakeholders. For subsequent rounds, the Working Group plans to obtain representation on the CCM itself and negotiate for a non-governmental entity to be the principal recipient of the grant.<sup>66</sup>

### **Next steps: strengthening women's representation and participation in the Global Fund**

As the world's leading multilateral investor in HIV/AIDS, tuberculosis and

malaria, the Global Fund serves as a key entry point for engendering the AIDS response and for accessing the necessary resources for women and people living with the disease. In advocating for more gender balance in its governance and operational structures and the inclusion of gender equality in its programming as a matter of policy, the Global Fund would be sending a powerful signal to other actors engaged in the response.

While the Gender Equality Strategy is an important step in this direction, clearer policies and additional guidance will support a more enabling environment for women's meaningful representation and participation. For Round 10, the Global Fund has modified the review criteria by which proposals will be assessed by the TRP in order to ensure alignment and consistency with recent policies adopted by the Board. In this regard, the TRP, in evaluating the 'soundness of approach' criterion, will look for proposals that use a situational analysis to assess the risk of, vulnerability to and impact of, the three diseases on women and men, girls and boys, as well as those proposals that adopt appropriate programmatic responses; empower women, girls and youth; promote gender equality; address the structural and cultural factors that increase risk and vulnerability; and contribute to changing harmful gender norms.

Despite some of the policy and operational gaps, key opportunities for coalition and partnership building do exist for women – particularly diverse coalitions of organizations – to access resources and to lead and shape the AIDS response in a way that accounts for their different needs. Women mobilizing at country level should advocate for a seat on the CCM. As the former gender representative of India's CCM, Subha Raghavan of Solidarity and Action Against The HIV Infection in India (SAATHII) proposed five strategies to strengthen the engagement of women in the AIDS response: initiate consultations with key stakeholders such as the Positive Women's Network; build

on the leadership, expertise and parallel activities of UNIFEM's efforts to engender the national response; create clear targets to ensure accountability; support gender trainings to strengthen expertise at the national level; and document the process so as to make the seat and the knowledge gained from sitting in it accessible to all.<sup>67</sup>

## Case Study 5

### Monitoring progress and holding governments accountable: community-based monitoring and evaluation<sup>68</sup>

Despite the international community's acknowledgement that gender inequality is one of the key drivers of the HIV and AIDS pandemic, and that women are particularly vulnerable and disproportionately impacted by the disease, most data collection, monitoring and reporting tools that are available at national and international levels are gender blind or at best gender neutral. Most of these tools comprise pre-determined quantitative indicators that do not explore or even pick up on social and structural relationships of power that enhance or hinder outcomes for individuals and groups. They also do not draw particular attention to the priorities of women or assess positive improvements in their lives in general or those of HIV-positive women in particular. On the other hand, community-based programme monitoring and evaluation tools tend to be more flexible, allowing for the collection and analysis of qualitative and quantitative data.

#### Positive women monitoring change<sup>69</sup>

In February 2005 the International Community of Women living with HIV and AIDS (ICW), in collaboration with the ActionAid-managed initiative Support for the International Partnership against AIDS in Africa (SIPAA), conducted workshops for women living with HIV in Lesotho and Swaziland. These workshops directly engaged women in the exercise of examining the national responses to the HIV

and AIDS pandemic in each country in relation to international policy commitments to which they were a signatory, such as the 2001 Abuja Agreement and the 2001 UNGASS Declaration of Commitment. In analysing these policy documents, positive women had the opportunity to assess the extent to which they addressed their rights, needs and concerns, and to see whether HIV-positive women had benefitted tangibly from these political commitments.

Positive women were then asked to develop their own monitoring and evaluation tool that was to be used by them for assessing progress on their self-identified priority issues, some of which are acknowledged by international policy documents while others are not. The resulting positive women monitoring change (PWMC) tool is a participatory monitoring instrument that has been used by HIV positive women in Eastern and Southern Africa, including HIV-positive young women (aged 18-30), whose voices are often excluded from decision-making fora, and whose rights, concerns and needs differ from those of older women and are usually overlooked as well by other actors working in the field of HIV and AIDS. The tool has been especially valuable in exploring positive women's knowledge and awareness of rights and issues that concern them, especially vis-à-vis access, care and treatment, sexual and reproductive rights and violence against women, in the context of their lived experiences of putting or attempting to put that knowledge into practice, and the challenges that they face in doing so.

It also considers the experiences and attitudes of service providers, assesses the strengths and weaknesses of available services, and identifies the constraints and barriers service providers face in providing quality care and support in resource poor, remote and under-prioritized settings. The PWMC tool also includes a survey that can be used to hold governments and ministries to account on their promises and to advocate on priority issues using

## Reflections on positive women's leadership

*"I think a lot of us, within the positive women's movement at least, struggle with the term 'leadership' because we view it as a traditional male concept of hierarchical action with which we, as feminists, feel uncomfortable. I think many of us who had key roles in ICW, for example, actually have felt quite uncomfortable with being named as the chair or officer of a network that is so huge and diverse in experiences, when we are so aware that we are supposed to be representing women from so many different countries, contexts and experiences. Somehow the very concept of 'leadership' clashes with the concepts of 'meaningful participation' and equitable representation for which we are striving. How can a positive woman who has not had children be expected to talk knowledgeably about the experiences of a positive diagnosis in relation to fears for her children? How can a positive woman who has not injected drugs talk knowledgeably about the added stigma attributed to her drug*

*use or the challenges of co-infection? How can a positive woman who is over 30 adequately represent a teenage positive woman. How can a non-African represent an African? And the list continues. Because our identities as people have so often and so roughly been torn out of us through our being labelled and branded as a 'PWA', we are all the more anxious to refine and regain control of our identities as individual women with our own experiences to describe, and to ensure that our collective voices are not just massed into one. Sadly, the concept of 'leadership', which often ends up with just a very few select individuals being singled out to represent so many others often then feels as if it is perpetuating that loss of separate identity.*

*"How then best to support all the positive women who are the true leaders around the world? It would be wonderful if this report enabled us to provide more positive women leaders of the future –*

evidence from both HIV-positive women and service providers, as well as from monitoring the progress of government commitments, including the Millennium Development Goals (MDGs).

### Lessons learned

By being placed at the centre, positive women found the process of developing the PWMC tool transformative. Having the opportunity to engage politically with their own experiences and environments, to envision a potentially different future and to shape their own messages, indicators or frameworks allowed them to create a contextualized 'ideal'. The PWMC tool has provided positive women with a useful framework to gather, analyse and

present information; to raise collective awareness among positive women of issues affecting their lives and mobilize around these issues; as well as to monitor performance and hold government accountable for translating their rights in policy and practice.

Participatory M&E provides stakeholders with a more well-rounded understanding of the outcomes and impacts of policies and programmes. Such an approach also allows stakeholders to analyse and examine the difficult-to-measure areas, such as the power dynamics within and among relationships; trust as well as risk; knowledge, attitudes and beliefs, including superstitions; and motivations as well as actions.

*for instance, through funds for mentoring them and enabling them to be trained and supported by us and come with us to meetings, so they can develop all their great skills without feeling overwhelmed with the onus of the sudden total responsibility of representation. Even 10 mentoring grants for individual positive women as interns for a year at a time – which is what World YWCA began to do – could make a huge difference to creating a new cadre of international young women positive leaders.”*

— Alice Welbourn, Founder of the Salamander Trust, Creator of Stepping Stones, and former Chair of ICW

*“There needs to be a serious commitment and adequate resources to mentor women with HIV to step forward into advocacy and policy arenas. There is too much tokenism – attempts to have a positive woman on a board, commission, etc. without support and training. This does not help create a pipeline of leader-*

*ship and is often a set up for failure individually and as a movement. Mentoring includes training on how to be effective in meetings, breaking down complex language, understanding roles and responsibilities and strategic understanding of how each forum can raise the profile of women living with HIV and their specific advocacy issues. Women also need practical support to become involved and stay involved in advocacy. This may mean transportation vouchers, food, child-care, flexible hours or hours that work within their schedule and stipends. This not only makes it financially possible but also lets women know that their time is important and valued. If support is not provided, we see a fairly homogenous group of women participate who are financially better off and do not necessarily represent the diversity of women who are HIV infected.”*

— Maura Riordan, formerly of WORLD and the Positive Women’s Network in the United States

## Conclusions

The common theme underscoring all five case studies is that realizing the power of participation necessitates significant investment in those who are most affected by HIV. Box 5 features extracts from interviews with two activists summarizing some of the key issues that emerged during all the interviews conducted for this report, particularly that women need access to resources and mentorship to facilitate their full involvement.

Obtaining a ‘seat at the table’ for women in the HIV and AIDS response also requires a number of other steps at the national and global level. These are outlined in the next chapter.

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## Chapter 4

# Recommendations for Advancing Women's Leadership and Participation

*"We must continue to demonstrate leadership and invest resources targeted to the priorities of women and girls; this includes addressing social, economic and legal factors that negatively impact on women. HIV and AIDS and persistent gender inequality are mutually reinforcing crises; we must tackle them together to achieve lasting change."*

— Ines Alberdi, Executive Director, UNIFEM, on the occasion of World AIDS Day, 1 December 2009

The meaningful participation and leadership of women, particularly those most affected by the epidemic, is an essential component of an effective and comprehensive response to HIV and AIDS. Influencing mechanisms and processes by which women become more active partners in defining and implementing solutions at the community, national and global level holds significant potential for transforming the AIDS response and has yet to be consistently implemented as a cross-cutting solution.

The need for sustained commitment to ensuring women are agents of change

rather than as recipients of services was echoed by women in places as diverse as Cambodia, South Africa, Thailand and the United States. Ten key recommendations emerged from the findings of this review and build on the many civil society statements calling for women's meaningful participation, full involvement and active leadership in the AIDS response. They are directed toward national governments, funders and other institutional leaders in the AIDS response and can also serve as an advocacy agenda for civil society stakeholders, particularly affected communities.

# Recommendations

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1. Recognize affected women, such as HIV-positive women, home-based caregivers, and young women, as key stakeholders in the AIDS response by reserving formal places for meaningful participation and leadership in decision-making bodies such as the Country Coordinating Mechanisms of the Global Fund to Fight AIDS, Tuberculosis and Malaria;
2. Develop definitions of and standards for meaningful participation through consultation with women, most importantly with 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, particularly as it pertains 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 fully in the HIV and AIDS response through leadership training, sustained technical support and mentorship in order 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, and respond to the immediate needs of women, including increased access to HIV prevention, testing, treatment, care and support services; and,
10. Strengthen gender expertise within formal decision-making bodies and funding mechanisms involved in the response to HIV and AIDS.

# Annex I: Interview and survey questions

## In-depth interview template

The interview template for in-depth interviews included the following questions:

### 1) What challenges do women face when participating in or leading the response to HIV and AIDS?

- Ask about challenges at the individual, household, organizational, legal, economic, social/cultural levels.
- Is it easier to participate and lead the HIV and AIDS response at the local, national or global level? Why? What makes it harder at the other levels?
- Are there opportunities for women to participate at the local, national and global level in your country? What are some of these?

### 2) What lessons have you learned and recommendations would you share about strategies to increase women's participation and strengthen their leadership, particularly of HIV-positive women?

- Are there certain platforms at the local, national or global level that we need to see more women represented on so as to be more effective in addressing women's issues?
- At the national level, ask about GFATM, PEPFAR, UNAIDS and other larger donors? Are women represented here? If yes, how? (Note name of network, NGO, INGO, advisory body etc.)
- Which groups are represented?

### 3) What is the role of civil society leadership on women and AIDS, including networks of HIV-positive women?

- Who speaks for women, girls and AIDS in your country – in civil society, in the Government, and the private sector? Does this person/network do a good job? If yes, what are some of the things

he/she has accomplished? If not, why is the person(s) not effective?

- Who speaks for positive women in your country – in civil society, within the Government and in the private sector?

### 4) Where does gender expertise exist and what effect does it have on the success or efficacy of programmes for women and girls? Can you share examples?

- Who has technical expertise in your country on women and AIDS policy and programmes? – ask about a person, an institution, a network or a government department.
- Can you tell me about some of the things that this person/ institution/ network/department has been able to achieve?
- Why do you think this person/ institution/network/department has been so effective?
- If not, why has the person/ institution/network/department not been effective?

### 5) What are the capacity needs to strengthen women's leadership and participation in the AIDS response?

- How can we ensure that more women become leaders in the AIDS response?
- What role can positive women and their networks play in the AIDS response?

## Global survey questions

- 1) Are there particular challenges or opportunities that women face when participating in or leading the response to HIV and AIDS? And how does this vary between the local, national and global levels?
- 2) What lessons have you learned and recommendations would you share about strategies to increase women's participation and strengthen their leadership, particularly HIV-positive women?
- 3) What is the role of civil society leadership on women and AIDS, including networks of HIV-positive women?
- 4) Where does gender expertise exist and what effect does it have on the success or efficacy of programmes for women and girls? Can you share examples?
- 5) What are the capacity needs to strengthen women's leadership and participation in the AIDS response?
- 6) Do women participate in the local or national AIDS coordinating authorities in your country? If so, where and at what level?
- 7) Are women's organizations and/or the women's sector represented in the local or national AIDS coordinating authorities in your country? If so, where and at what level?
- 8) Do HIV-positive women and/or HIV-positive women's organizations participate in the local or national AIDS coordinating authorities in your country? If so, where and at what level?
- 9) Do women participate in the Country Coordinating Mechanisms of the Global Fund to Fight AIDS, TB, and Malaria (GFATM) in your country? If so, how many?
- 10) Are women's organizations and/or the women's sector represented in the Country Coordinating Mechanisms of the GFATM? If so, how many? And by whom?
- 11) Do HIV-positive women and/or HIV-positive women's organizations participate in the Country Coordinating Mechanisms of the GFATM? If so, how many? And by whom?

## Annex II: Key informants and respondents

Adekemi	Siphiwe Hlophe	Luisa Orza
Calle Almedal	Beri Hull	Lucy Owusu-Darku
Hoang Thi Le An	Nkiru Igbokwe	Dean Peacock
Leah Kusah Anzani	Asha Juma	Mony Pen
Dawn Averitt Bridge	Musimbi Kanyoro	Patricia Perez
Bukola Ayinde	Johanna Kehler	Kousalya Periasamy
Sandra Banda	Tamil Kendall	Sophie Pinkham
Shannon Behning	Konjit Kifetew	Judith Polsky
Emma Bell	Saboi Kwalombota	Proscovia
Louise Binder	Monruedee Laphimon	Ingrid Quinn
Jennifer Bushee	Beatrice Lukalo	Robin Ridley
Helena Choi	L.M.	Maura Riordan
Kathleen Cravero	Vandana Mahajan	Violeta Ross
Gladys Damalin	Shari Margolese	Cynthia Rothschild
Nazneen Damji	Terry McGovern	Asia Russell
Anne-Christine d'Adesky	Caroline McArthur	Lisa Schechtman
Maria de Bruyn	Aurorita Mendoza	Kristan Schoultz
María Lorena Di Giano	Inviolata Mmbwavi	Esther Shaheema
Sophie Dilmitis	Moira Moakamela	Akhila Sivasdas
Elsie	Linda Morales	Leah Stephenson
Esnart	Pamela Morrison	Lauren Suchman
Elisabet Fadul	Sisonke Msimang	Ida Susser
Natalie Fisher	Neelanjana Mukhia	Martha Tholanah
Janet Fleischman	Lydia Mungherera	Kate Thomson
Jebbeh Forster	Patricia Nalls	Belinda Tima
Lynde Francis	Gcebile Ndlovu	Reshma Trasi
Susana Fried	Thao Nguyen	Liz Tremlett
Anna Fumarola	Alessandra Nilo	Ale Trossero
Jennifer Gatsi	Jemimah Nindo	MariJo Vazquez
Jacob Gayle	Esse Nsed	Asunta Wagura
Shuangyan Gong	Nwe	Alice Welbourn
Anand Grover	'Rolake Odetoyinbo	David Winters
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**UNIFEM**  
304 East 45th Street  
15th Floor  
New York, NY 10017 USA

Tel: +1 (212) 906-6400  
Fax: +1 (212) 906-6705  
[www.unifem.org](http://www.unifem.org)  
[www.genderandaids.org](http://www.genderandaids.org)

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*People living with HIV/AIDS hold placards during a protest rally in New Delhi on May 4, 2010, against the termination of service of 1,000 outreach workers.*

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**ATHENA Network**  
E-mail: [admin@athenanetwork.org](mailto:admin@athenanetwork.org)  
[www.athenanetwork.org](http://www.athenanetwork.org)