

In Women's Words

ACTION AGENDA



- Ensure comprehensive and inclusive HIV services that address the visions, life-long needs, and rights of women and girls in all our diversity.
- Eliminate stigma and discrimination, and ensure full protection of the human rights of all women and girls, including our sexual and reproductive rights.
- Strengthen, invest in, and champion our leadership and equality to ensure the full and meaningful participation of women and girls, in particular those of us living with and affected by HIV, in the HIV response.
- Empower us to be catalysts of social justice and positive change, and eliminate all forms of violence against us.
- Ensure full access to information and education, including comprehensive sexuality education for all women and girls.

“ NOTHING SHORT OF A SOCIAL REVOLUTION IS NEEDED TO DELIVER ON THE COMMITMENTS WE HAVE MADE TO WOMEN, GIRLS, AND GENDER EQUALITY. ”

— UNAIDS Executive Director Michel Sidibé

“ IF WE ARE TO TRULY CHANGE THE COURSE OF THE EPIDEMIC, INVESTING IN WOMEN'S EMPOWERMENT IS ESSENTIAL. ”

— UN Women Executive Director Michelle Bachelet

Building women's and girls' global meaningful participation in the High Level Meeting on AIDS

A global virtual consultation in nine languages, engaging approximately 800 women from over 95 countries, was undertaken to provide a platform for women and girls - especially women living with and affected by HIV - to voice their priorities and vision for the future of the HIV response. The consultation aimed to take stock of women's

experiences of the measures in place to curb HIV to date; and to ensure women's and girls' voices are heard in the High Level Meeting on AIDS in June 2011.

The consultation was defined by 5 principles: 1) Inclusion of women and girls in decision-making, including the **democratization** of global processes;

2) Importance of women, girls, and gender **equality**; 3) Centrality of women's **rights** to the success of the HIV response; 4) Political opportunity to **define actions and address women, girls, and gender equality in the context of HIV**; and 5) Urgency of all **Millennium Development Goals** to the well-being of all women and girls.



Scanning the global landscape since 2001 for **Women, Girls, Gender Equality, and HIV**

The global virtual consultation utilized the following ten building blocks of the HIV response to review the successes and challenges since 2001, informed by the lived expertise of women and girls.

1: Meaningful involvement of women and girls living with and affected by HIV

“Women from vulnerable groups can provide practical advice not found in any literature; this is always a new look and a new vision. In my particular personal opinion, women (who went through hell) should be maximally involved in the work.”

(Eastern Europe and Central Asia)

The Commitment: The UNGASS Declaration 2001 commits to ensuring “... the full participation of people living with HIV/AIDS, those in vulnerable groups and people most at risk, particularly women and young people” (para 37). The 2006 Political Declaration on HIV and AIDS recognizes the need to “... support greater involvement of people living with HIV” (para 15), and the need to strengthen leadership “... on the part of all stakeholders, including people living with HIV, civil society and vulnerable groups.”

The Reality: While women and girls living with and affected by HIV are on the frontlines of the HIV response leading change, our involvement in policy setting and related decision-making processes remains a major challenge and resources remain largely inaccessible for women’s groups, in particular those living with HIV. Achieving meaningful involvement in the HIV response requires, at minimum, 1) recognition of the relevance of our expertise for an effective HIV response for women and girls; 2) commitments to include women and girls living with and affected by HIV in decision-making for effective processes and outcomes; 3) investment in networks and organizations of women living with and affected by HIV; and 4) access to local, national, and international decision-making bodies.

2: Solidarity with women and girls living with and affected by HIV

“Sex workers experience debilitating stigma and discrimination that erode their ability to protect their health and well-being. Stigma decreases their ability to seek protection from the courts or the police when experiencing violence and discrimination. HIV programs should teach sex workers about their legal and human rights towards a renewed sense of dignity which will compel them to collectively demand justice and relief from discriminatory practices.”

(Asia and the Pacific)

The Commitment: The UNGASS Declaration 2001 emphasizes the need to “... confront stigma, silence and denial; address gender and age-based dimensions of the epidemic; and, eliminate discrimination and marginalisation” (para 37). The 2006 Political Declaration on HIV and AIDS commits to “... intensifying efforts to ... eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and developing strategies to combat stigma and social exclusion connected with the epidemic” (para 29).

The Reality: Thirty years into the HIV epidemic, HIV-related stigma and discrimination persist, and continue to pose significant barriers to successful HIV responses. Women living with HIV experience particular forms of stigma and discrimination, especially in relation to our perceived or actual roles as mothers and carers, in accessing services such as sexual and reproductive health, and in claiming our rights. Women belonging to key affected populations are often doubly stigmatized on the basis of gender and age, sexual orientation and gender identity, use of drugs, experience of prison, disability, migration status, or profession – including sex work. We call for a greater effort to eliminate the stigma and discrimination faced by women living with HIV and other key affected women, particularly within health services.



3: Safety for all women and girls

“The issue of violence against women is one thing and against women living with HIV is another. All the women living with HIV in my organization have been subjected to various forms of violence before and after diagnosis, from sexual violence, psychological, economic to institutional violence. The most important lesson for us is that we are able to talk about this issue and from identification [of it], support each other and make joint decisions to seek help and improve our quality of life.”

(Latin America)

The Commitment: The UNGASS Declaration 2001 ensures “development and accelerated implementation of national strategies for ... reduction of their vulnerability to HIV/AIDS through the elimination of all forms of discrimination, as well as all forms of violence against women and girls ...” (para 61). The 2006 Political Declaration on HIV and AIDS reinforces this and further commits to the reduction of their vulnerability to HIV/AIDS through the elimination of all forms of discrimination, as well as all types of sexual exploitation of women, girls and boys, including for commercial reasons, and all forms of violence against women and girls, including harmful traditional and customary practices, abuse, rape and other forms of sexual violence, battering and trafficking in women and girls ...” (para 31).

The Reality: The dual epidemics of HIV and violence against women and girls, and the fact that violence is both a cause and consequence of HIV, are now widely recognized. As a result, new policy and legislative frameworks, and advocacy and funding campaigns are increasingly in place. Nonetheless, women and girls continue to be subjected to multiple and overlapping forms of violence, such as psychological, sexual, physical, institutional, and structural violence, reinforced by harmful socio-cultural practices. Many marginalized women, including women in sex work; women who use drugs; and lesbian, bisexual, and transgender women and men, are also especially exposed to violence. The HIV response must improve efforts to address violence against women and girls, particularly against women living with HIV.

4: Acceleration of gender equality through the HIV response

“Most of the HIV prevention programs [focus on reducing] risk factors that increase the possibility of getting HIV (number of sexual partners, use of condoms, etc). Almost no HIV prevention or care program is directed to reduce the vulnerability conditions in which women acquire HIV (for example poverty, violence, gender roles, lack of education, lack of leadership).”

(Latin America)

The Commitment: The 2006 Political Declaration on HIV and AIDS pledges to eliminate gender inequalities and to “ensure that women can exercise their right to have control over, and decide freely and responsibly on, matters related to their sexuality in order to increase their ability to protect themselves from HIV infection, including their sexual and reproductive health, free of coercion, discrimination and violence; take all necessary measures to create an enabling environment for the empowerment of women and strengthen their economic independence; and, reiterate the importance of the role of men and boys in achieving gender equality” (para 30).

The Reality: Since 2001, attention to the gender dimensions of HIV has grown. The HIV epidemic has necessitated increased focus for advancing gender equality to ensure better and more successful HIV prevention, treatment, care, and support. We call for stronger alliances between the HIV movement and the women’s rights movement: to reinforce advocacy for gender equality and disability equity, within the context of HIV, and to enable all women to seek greater autonomy over our sexual and reproductive health and rights, as well as greater economic independence.

5: Integrated services, especially sexual and reproductive health and HIV

“It is important to note positive changes that have occurred over the last 10 years, particularly in relation to access to health services, including SRH services to women living with HIV. Increased access to ART has clearly contributed to an increase in the type of services available to women living with HIV, particularly cervical cancer screening and family planning methods available.”

(Asia and the Pacific)

The Commitment: The 2006 Political Declaration on HIV and AIDS emphasizes the need to “... strengthen policy and programme linkages and coordination between HIV/AIDS, sexual and reproductive health ...” (para 21); “increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection, principally through the provision of health care and services, including, inter alia, sexual and reproductive health” (para 30), and to “... strengthen health and social systems by integrating HIV/AIDS intervention into programs for ... mother and child health, sexual and reproductive health, tuberculosis, hepatitis C, sexually transmitted infections, nutrition, children affected, orphaned or made vulnerable by HIV/AIDS as well as formal and informal education” (para 34).

The Reality: The consultation identified the increasing availability of successful approaches for linking services - in particular those that aim to address the sexual and reproductive health and rights of women living with HIV, and marginalized and key affected women. However, comprehensive services remain an exception, requiring accelerated action for an effective HIV response tailored to women and girls in all our diversity. Women identified an essential package of integrated HIV and sexual and reproductive health and rights-related services, including: youth friendly services; a full range of contraceptive choices; the ability to decide responsibly and freely whether and when to have children; access to STI and cervical cancer prevention, screening, and treatment; access to post exposure prophylaxis and emergency contraception; harm reduction measures; and access to services to support safe conception, pregnancy, childbirth, and infant feeding.

6: Sexual and reproductive health and rights of women living with HIV to receive comprehensive peri-natal care and to have children free of HIV

“Community structures offering ANC do not provide a comprehensive package for HIV positive pregnant women. Women and girls living with HIV are not informed when and how they can get pregnant and men do not always accept to accompany their spouses to antenatal visits. It is really important to make special emphasis on the promotion of PMTCT in the community by involving more women, youth, and PLWH networks.”

(West and Central Africa)

The Commitment: The UNGASS Declaration 2001 commits to “... growing the availability of efficient treatment to reduce the transmission of the virus from mother to child and giving access to treatment for HIV-infected women and babies, ... to include psychological support and the voluntary and confidential testing services ...” (para 54). The 2006 Political Declaration on HIV and AIDS commits to: “ensuring that pregnant women have access to antenatal care, information, counselling and other HIV services; increasing the availability of and access to effective treatment to women living with HIV and infants in order to reduce mother-to-child transmission of HIV; and, ensuring effective interventions for women living with HIV, including voluntary and confidential counselling and testing, with informed consent, access to ... life-long anti-retroviral therapy and, where appropriate, breast-milk substitutes and the provision of a continuum of care” (para 27).

The Reality: While significant progress is being made to increase HIV-free delivery, women face major challenges in terms of securing our sexual and reproductive health and rights, at risk of being treated as ‘vessels’ and ‘vectors’ of sick babies and disease. While prevention of HIV transmission to babies has served as an important entry point for HIV prevention and treatment services for women and families, this approach alone is reductionist and inadequate. Moreover, utilization of peri-natal services is hampered by fear of coerced and/or mandatory HIV tests and positive results as well as by abusive, judgmental attitudes and treatment by healthcare providers, particularly for marginalized women. These rights violations undermine efforts to improve all maternal and child health, as well as HIV care. Integrated sexual and reproductive health and HIV prevention, care, and treatment services must be available and accessible for all women and girls, within and beyond the peri-natal setting, requiring accelerated operationalization of the WHO-endorsed four-pronged strategy to prevent vertical transmission.

7: Women-centered HIV prevention technologies

“Female condoms continue to be more expensive and less readily available than male. Women living with HIV outside of activist communities, or without good access to support groups and information may not be aware of the existence or development of new female centered technologies, their implications, or the debates around them.”

(North America and Western Europe)

The Commitment: The 2006 Political Declaration on HIV and AIDS commits to intensifying efforts to ensure “... expanded access to ... female condoms” (para 22) and to “... intensifying investment in and efforts towards the research and development of new, safe and affordable HIV/AIDS-related medicines, products and technologies, such as female-controlled methods and microbicides” (para 45).

The Reality: The HIV prevention research field has yielded promising results, with recent breakthroughs in women-centered prevention technologies. However, access to existing technologies continues to pose challenges as women globally cite an unmet demand and need for female condoms. While most notably the proof of concept for a microbicide has been achieved, much more investment needs to be directed to research in women-centred prevention technologies (such as microbicides and female condoms; pre- and post-exposure prophylaxis; microbicides for women with HIV), as well as in ensuring availability of and access to these technologies for all women.

8: Comprehensive sexuality education

“Sex education and sexuality issues in my country remain a taboo, leading to the high incidence of HIV in youth.”

(Latin America)

The Commitment: The UNGASS Declaration 2001 guarantees that young people of both genders “... have access to information, education, including peer education and specific education for youth about HIV, as well as the necessary services to develop the required abilities to reduce their vulnerability to the HIV infection; all of this in collaboration with young people, mothers and fathers, families, educators and health care professionals” (para 53). The 2006 Political Declaration on HIV and AIDS commits to “... addressing the rising rates of HIV infection among young people to ensure an HIV-free future generation through the implementation of comprehensive, evidence-based prevention strategies, responsible sexual behavior, including the use of condoms, evidence- and skills-based, youth-specific HIV education, mass media interventions and the provision of youth-friendly health services” (para 26).

The Reality: Whilst countries increasingly recognize the need for comprehensive, rights-based, and evidence-informed sexuality education, consistent access to comprehensive gender-sensitive sexuality education within and outside schools, particularly for young women in all their diversity, is still inadequate or even lacking. Young women and girls require the necessary knowledge and skills to protect themselves against HIV, to uphold the rights of those who have HIV, and for all to lead healthy, productive lives.

9: Investment in care and caregivers

“Home-based care work is only recognised on paper and in speeches, and does not translate to supporting the carer at the community level.”

(East and Southern Africa)

The Commitment: The 2006 Political Declaration on HIV and AIDS commits to “... providing support and rehabilitation to ... women ... particularly in their role as caregivers;” (para 32) and recognizes the need to “... meet the urgent need for the training and retention of a broad range of health workers, including community-based health workers; ...” (para 35).

The Reality: Women leaders, providing care in their communities, are becoming increasingly mobilized and visible – yet they still lack adequate recognition, support, training, supplies, or remuneration for all their work. In addition, female health service providers living with HIV experience significant levels of stigma and silence, affecting their own health seeking behavior for effective treatment. Women and girls further seek to more equitably share caregiving with men and boys in their communities.

10: An HIV response that works for women and girls in all of our diversity

“Minority groups such as sex workers or migrants often avoid health services for fear of discrimination or judgmental treatment.”

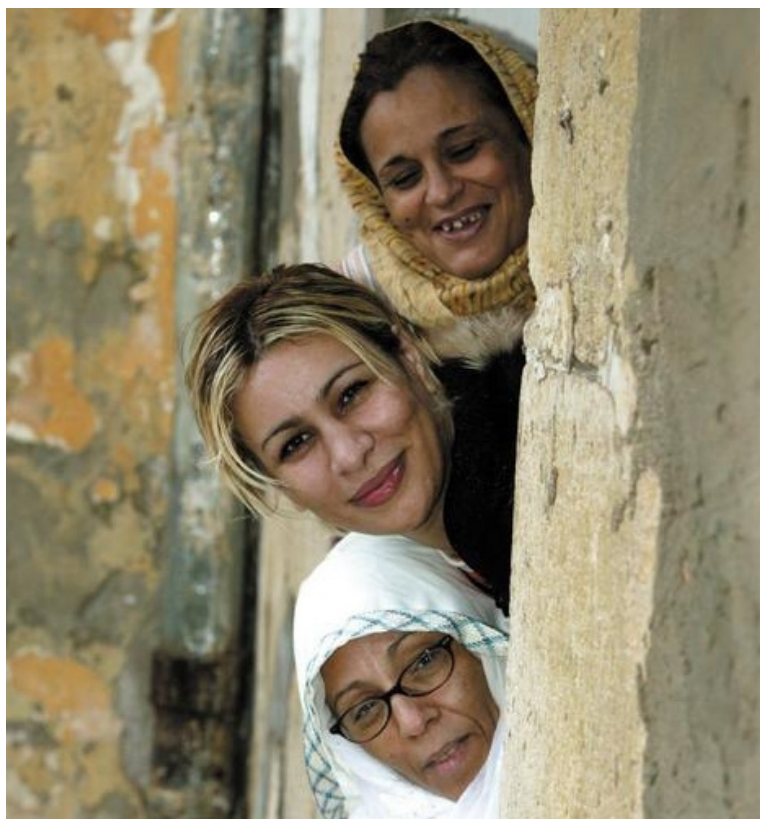
(Caribbean)

The Commitment: The 2006 Political Declaration on HIV and AIDS commits to “achieve broad multisectoral coverage for prevention, treatment, care and support, with full and active participation of people living with HIV, vulnerable groups, most affected communities, civil society and the private sector, towards the goal of universal access to comprehensive prevention programs, treatment, care and support by 2010” (para 20) and resolves to “... integrate food and nutritional support, with the goal that all people at all times will have access to sufficient, safe and nutritious food to meet their dietary needs and food preferences, for an active and healthy life, as part of a comprehensive response to HIV/AIDS” (para 28).

The Reality: Women and girls from every region articulated a clear desire for an HIV response that engages and addresses women and girls in all our diversity, regardless of age, HIV status, sexual orientation, or socio-economic status. Increase in uptake of HIV services will only occur when services respond to the realities and needs of all women and girls, including those of us living in rural and hard-to-reach areas, young women, women living with HIV, women with disabilities, women in conflict areas, transgender women, women who have sex with women, women involved in sex work, refugees, women who use drugs, and indigenous women.

Acknowledgements

The ATHENA Network and the Global Coalition on Women and AIDS acknowledge and appreciate our outstanding team whose collaboration, investment, and shared expertise has made a virtual consultation for women and girls, and this action agenda, toward the 2011 High Level Meeting on AIDS possible.



Lead authors and coordinating team
Luisa Orza (ATHENA)
Tyler Crone (ATHENA)
Claudia Ahumada (GCWA)
Alice Welbourn
(Salamander Trust)

GCWA team
Jantine Jacobi (UNAIDS)
Nazneen Damji (UN Women)
Kreena Govender (UNAIDS)
Matthew Cogan (UNAIDS)

Regional focal points and technical experts

East and Southern Africa
Lydia Mungherera
Esther Mwaura-Muiru
Leah Okeyo
Johanna Kehler
Mmapaseka Steve Letsike

West and Central Africa
Assumpta Reginald

Middle East and North Africa
Valli Yanni

Asia and the Pacific
Ishita Chaudhry
Rathi Ramanathan

Caribbean
Olive Edwards

Latin America
Eugenia Lopez Uribe
Violeta Ross
Tamil Kendall

Eastern Europe and Central Asia
Anna Zakowicz

North America and Western Europe
Ebony Johnson
Silvia Petretti

Key collaborators
Lilian Abracinskas
Judith Bisumbu
Juliana Davids
Shannon Hayes
Zhenya Maron
Inviolata Mbwavi
Svetlana Moroz
Alessandra Nilo
Isabel Nuñez
Hendrica Okondo
Erin O'Mara
MariJo Vazquez
Anandi Yuvraj

A Decade Later: Top 5 Priorities to move us forward and beyond 2011

The consultation confirmed that: Women seek and are eager to be **engaged** and viewed as **equal, active** stakeholders and agents of change rather than as subordinate, passive recipients. Women seek an HIV response that is **deeply rooted in human rights, equitable, holistic, gendered, and shared sector-wide**. Women around the globe are taking **initiative** and are on the **frontlines** of the HIV response, bringing about change in their communities.

- 1 Ensure comprehensive and inclusive HIV services that address the visions, life-long needs, and rights of women and girls in all of our diversity:** Ensure accessible, gender-sensitive, rights-based, voluntary, and integrated HIV and sexual and reproductive health services for all women, regardless of age, HIV status, sexual orientation and gender identity, or socio-economic status.
- 2 Eliminate stigma and discrimination, and ensure full protection of the human rights of all women and girls, including our sexual and reproductive rights:** Stigma adds to the existing burdens of illness, lack of time, poverty, limited access, and care, faced by us women living with HIV and

other most affected women. Achieving solidarity equals ending stigma and discrimination against women and girls, in particular women and girls living with HIV, and key affected women and girls, and the repeal of punitive laws that criminalize us on the basis of drug use, sex work, sexuality, or HIV transmission and exposure.

- 3 Strengthen, invest in, and champion our leadership and equality, to ensure the full and meaningful participation of women and girls, in particular those of us living with and affected by HIV, in the HIV response:** Promote gender equality through investment in women's empowerment, ensuring representation in national decision-making fora, participation in the development and implementation of gender-responsive National Strategic Plans on HIV, and access to funding for women's groups, in particular those living with HIV.
- 4 Empower us to be catalysts for social justice and positive change, and eliminate all forms of violence against us:** Achieve an enabling environment for women and girls and eliminate gender-based violence in all its forms through the promotion of women's

human rights, and recognize and respond to gender-based violence as a cause and consequence of HIV.

- 5 Ensure full access to information and education, including comprehensive sexuality education for all women and girls:** Insist that all women and girls have comprehensive access to information, education, and awareness around HIV, sexuality, and reproduction.

The **most affected** women and girls must be most **central** to the response. History has shown us repeatedly, where true social transformation has taken place, if these same women's visions and aspirations were adequately supported, then the aspirations of us all would fall into place.

PROMOTE THE GREATER PARTICIPATION OF ALL KEY AFFECTED WOMEN IN DECISION-MAKING THAT AFFECTS THEIR LIVES.

— EAST AND SOUTHERN AFRICA

Collaborating Partners



Additional Supporting Partners

Asia Pacific Network of Women with HIV, (WAPN+), Thailand
 EATG, Europe
 Echos séropos, Belgium
 ICW North America, USA
 International Women's Health Coalition, Global
 Mama's Club, Uganda
 Seres, Portugal
 UK Consortium on AIDS and International
 Development, UK

This action agenda is co-sponsored by the Joint United Nations Programme on HIV/AIDS and the United Nations Entity for Gender Equality and the Empowerment of Women.

For more information, please visit www.womenandaids.net and www.athenanetwork.org or contact us by email at info@womenandaids.net and admin@athenanetwork.org.