

“Women are bearers of HIV, of violence, and despite some ‘good’ policies, the numbers for young women aren’t changing, if anything they are getting worse.”



Gender, rights and diversity: Connecting the pieces

Making the Global Fund work for women

This paper examines a series of opportunities for strengthening women’s engagement with the Global Fund to Fight AIDS, Tuberculosis and Malaria and proposes solutions that work from local to global.

The paper draws from discussions and experiences that came out of a collaboration between AIDS Legal Network (ALN) and ATHENA Network, in partnership with Access Chapter 2 (AC2), South Africa, International Community of Women Living with HIV East Africa (ICWEA), Uganda, and Coalition of Women Living with HIV and AIDS (COWLHA)

in Malawi, and is funded by the German development agency GIZ’s BACKUP Initiative.

The collaboration aimed to strengthen women’s engagement with the Global Fund as it implemented a new funding model, from June to December 2014 and included:

- country-led workshops to raise awareness of Global Fund structures and processes at country level
- in-country dialogues highlighting the need and urgency for prioritisation of women’s issues in relation to HIV
- support for the participation of women living with and most affected by HIV, in country dialogues and concept note development processes
- a stakeholder dialogue on gender, rights and diversities in the Global Fund new funding model in London, to share and distil lessons from country experiences, and challenge development partners to define their role in transforming the lives of women and girls in all of their diversity.

1. Connecting the Global Fund and the women it aims to serve

Women who rely on antiretrovirals funded by the Global Fund need as much awareness of its purpose, mandate,

function and funding, as voice and agency within its processes and structures. Without this, it is impossible for women served by the Global Fund to engage with, influence or hold it to account.

“What is this animal called the Global Fund?”

“I feel everyone should know. Anyone who is living with HIV should know what is happening for them. They feel that the next thing that happens for them is death. If they know a little bit about what is happening it tends to be a negative thing – we know there is money but they feel others are using it for their own gain ... they feel that ‘my virus is what they are benefiting from’ which is bad.”

Across the workshops and discussions our consortium held, it was clear that from



2. Connecting women’s organizations and the resources they need to meaningfully engage

Women’s organizations need to be adequately and sustainably

resourced to support their engagement in Global Fund structures and processes and other national policy processes.

Much of the work of women attempting to engage in national policy processes

communities to provincial level leadership and beyond, the very women identified by the Global Fund as ‘beneficiaries’ are unaware of its role and mandate, how they can engage in its structures and processes, or how they could access its resources. Those who had heard of the Global Fund did not have any clear idea what it could mean for women.

In order to fully realize rights and responsibilities as women living with HIV, women at all levels need to know what is being said and done on their behalf; who is representing their interests; where their interests are represented; and what processes and structures influence national policy and responses to women and HIV. Without this knowledge, women cannot track whether the issues they raise at local or provincial level are being addressed, and/or be partners in making the aims and ambitions of the Global Fund a reality.

“I had no knowledge about how the structure works and functions, I am expected to lead and advise the structure however limited orientation about the structure, its system and how to best utilize the leaders as elected, sometimes it seems like rubber stamping processes, because our issues are not reflected after engagements.”

(country dialogues, direct engagement with Country Coordinating Mechanism (CCM) representatives, participation in National Strategic Plan development processes, etc.) is resource intensive, but often un- or under-funded, and therefore relies on the support of a “host” network or organization, or on personal means.

“The process of engaging with the CCMs and the National AIDS Council is a rigorous exercise, it requires more time, resources and importantly human resources because this engagement should be done from an informed position – so a lot of reading, research must happen.”

This lack of adequate resources and supports often results in uneven engagement, and

potentially exposes women to tension and conflict in the home with family resources (time, money, energy) sustaining activities.

“You wake up in the morning and say you are going to work, but you do not get paid, and often at home you are asked why are you doing this?”

Further, women’s organizations have made an art-form of stretching what little money they do receive to its absolute limit, often relying on the volunteerism of their members and the

personal dedication and sacrifice of leaders. This sets an expectation of the amount of work that can be done on very limited resources among donors, who continually expect money to go further and do more.

“As volunteers we are often marginalized, as we are not able to follow through with work and resources so when decisions are made and you don’t have the means to do the work, even transport to get you somewhere including attending the meetings sometimes is a hustle.”



3. Connecting gender analysis and gender responsive programming

Women show a deep and nuanced understanding of power and structural issues underlying

gender inequality, but face challenges in prioritizing and programming for women’s needs.

Women need to be invited to define solutions, and not only describe challenges, so that innovation and transformation are truly based on and informed by women’s realities, risks, needs and desires. As new ideas and new solutions emerge, women leaders require ongoing support to strengthen their knowledge and awareness around the latest research and

evidence for women-centered HIV responses. By stepping up women’s immersion in the latest research and expanding women’s opportunities to speak to solutions, we can begin to redress the broader gender bias in the evidence base – especially in peer reviewed literature – and expand the array of interventions that benefit women.

When asked to suggest programmatic approaches to address structural determinants that undermine women’s ability to access HIV prevention, care and treatment, as well as to address pervasive gender-based violence, women in a number of the workshops/dialogues reverted to approaches that are strongly critiqued for gender blindness, i.e. “ABC” approaches and prevention of mother-to-child transmission, or they simply didn’t know where to begin.

“Discussions on women-centered prevention began and ended with access to female condoms.”



4. Connecting principle recipients and community-based organizations

Stronger accountability mechanisms are needed to ensure

funding reaches the communities it aims to serve. This includes capacity-building to equip community-based organizations (CBOs) and women’s networks to act as recipients of Global Fund grants.

Principle recipients (PRs) in most countries include government bodies (sometimes exclusively) and large national non-governmental organizations (NGOs),

network secretariats, or national offices of international NGOs. There are examples of disconnects both between PRs and the National AIDS Councils (NACs), whereby PRs are not necessarily represented on the NAC, and also between PRs and people operating at the district/community level, whereby funding often goes to sustaining the operating costs of the PR, and doesn't actually reach the community it is intended to benefit.

Funding modalities are often highly complex and may require levels of existing funding, minimum requests which can be much more than small entities can manage, and take skills and resources to apply for. CBOs often face a "chicken-and-egg" situation whereby they lack capacity to access funds, and they need funds to build their capacity. Yet without their engagement, issues affecting women at a community level are however easily overlooked in country dialogues and processes of prioritisation.

"Community-based organizations are the ones that are going to create change, but they can't

because they are too small to access funds. There is an urgent need to capacitate CBOs to access funds."

"How are we supposed to reach women on the ground if no-one is willing to fund these organizations?"

The Global Fund is advocating for countries to be capacity building CBOs through Community Systems Strengthening (CSS) grants. However, these tend to be focused on capacitating community health workers in line with recommendations from World Health Organization (WHO) guidelines and task shifting, rather than community strengthening more broadly. This leaves CBOs un- or under-resourced to meaningfully participate in and engage with Global Fund processes and structures, and to ensure women's realities, risks and needs are at the center of the response. To enhance CBO capacity and engagement, the criteria under which CSS grants are currently approved and implemented need to be evaluated.



NATIONAL LEVEL

5. Connecting women's rights and key populations

Women need to work within and across key population groups to break down the "either/or" categorization of women and key populations, and to bring a gender equality perspective across both.

A key populations focus can remove a gender lens, and overlook the many ways in which identities overlap and intersect. We create divisions between women as women and women as members of key affected

populations, including (among others) women who do sex work, women who use drugs, women who have sex with women, and transgender women. This division creates competition for the same resources, and prioritisation in programs. Women need to challenge gender norms and attitudes to create a coherent agenda that is inclusive of all their diversity and recognizes all of their intersecting identities.

A unique element of the dialogues in South Africa was to bring women's leaders from different sectors to create a new space where women met and were in dialogue as women in all of their diversity. This provides capacity and mandate to create an advocacy agenda that speaks to women in all of their diversity

rather than a splintered advocacy agenda that, for example, pits women living with HIV against women from key affected populations,

or young women, and fails to recognize common factors underlying women's marginalization in different contexts.



6. Connecting CCMs and constituencies

Greater commitment is required at national and global level to ensure that women's representation on CCMs is meaningful, translates into a

women-centered agenda and response, and affords the space for a two-way dialogue and accountability between women and their representatives at CCMs

Despite increased efforts and willingness on the part of both the Global Fund Secretariat and individual CCMs to increase meaningful engagement with, and representation of, women and their communities, accountability gaps between the CCM representatives and constituencies remain a challenge. These include:

- **Specific representation of women within the represented constituencies** (people living with HIV, civil society, private sector, etc). For example, women from key affected populations may be represented by one "key population" seat – not necessarily held by a woman – who is expected to speak on behalf of a huge range of diverse issues.

"What can a man from the LGBTI sector say about issues affecting women who do sex work?"

In some instances, this pattern of misrepresentation is repeated at the level of fund disbursement. South Africa is the only country to receive funding for women who have sex with women, but

the recipient of this funding is a men's organization as a result of women who have sex with women being grouped together with men who have sex with men.

Thus, while there may be a requirement for women to constitute a certain percentage of seats on the CCM, the representation of women per se, although a crucial aspect of enhancing women's participation in and engagement with these processes, does not necessarily equate to representation of women's realities, risks, needs and priorities. Women's representation needs to translate into women-centred approaches and responses.

- **Lack of formal and resourced consultation and feedback mechanisms between community representatives and their constituencies.**

"There is [no] mechanism that provides the funding and support for consultation and feedback – this therefore limits access to these processes by women and importantly engagement with the representatives."

- **Gate-keeping and bottle-necking.** In countries with fewer networks and organizations representing people living with HIV and key populations, these are often recipients of Global Fund funding, and may on that basis be excluded from sitting on the CCM. Alternatively, the seats may be occupied by a small number of people with the requisite expertise, which can give rise to gate-keeping, where information from communities are channelled to the CCM through very few representatives of these communities.



7. Connecting paper and practice

Women's organizations need to be capacitated, supported and resourced to meaningfully engage with policy and program development and implementation from design to evaluation.

Policies are improving in terms of language and commitment to women, girls, gender equality and rights. However, challenges remain in their implementation that urgently need to be addressed. Money, programs, and interventions intended to benefit women are still failing to bring about substantive and sustainable changes in the reality of women and girls at a community level.

There is a huge disconnect regarding national and provincial levels, who holds information, who informs programs and how the programs benefit women in their diversity at local and grassroots levels. The ethos of grassroots-informed programming is lacking and that impacts the accountability mechanism and monitoring of the HIV, TB, and STI response in the country.

An analysis of the first 20 concept notes submitted through the Global Fund's new funding model showed that gender-based violence was frequently included in the narrative, but that programming to address this was not costed and budgeted, or that gender programs were only included in the "incentive funding", which is not guaranteed to countries.

Country experiences to date indicate the need for technical support to be more available and accessible for community-based and/or women-led organizations, and tailored to the specific country or community context. Outside consultants brought in to draft concept notes – even if gender experts and conversant with the issues – cannot provide on-going and lasting support, or champion the country process from beginning to end, to ensure that women's needs and priorities are not lost along the way. They need to engage women's organizations and networks, and these need to be capacitated to do that budgeting and costing work.

"If you want gender transformative programming, you have to unpack HIV prevention. What does it mean, what interventions, how much do they cost, are they cost effective? Deepen the understanding of why gender transformative programming is needed."

In Uganda, a Health Systems Strengthening concept note prioritized capacity building and financial assistance for networks of women living with HIV. This success was due to a combination of able leadership from civil society; support from the Ministry of Health, Uganda AIDS commission, and the UN family and especially UN Women. Similarly, women living with HIV reported being able to present their needs and priorities for both the National Strategic Plan on HIV and AIDS (NSP) and the concept note development for the Global Fund. Priorities were taken up in the NSP. It is as yet unclear as to whether they were addressed in the concept note, submitted in October 2014.





8. Connecting the bio-medical and social/structural aspects of the response

Bio-medical advances must be accompanied by structural changes so that women and girls in all their diversity have choice and agency to access

and benefit from available services and realize rights.

“The extent to which we are actually taking the courage to act with decisiveness and honesty about what it really and actually takes to effectively address the epidemics [of HIV and gender-based violence] is limited or uneven at best.”

Decades into the HIV epidemic, persistent gender inequality and human rights violations that place women and girls at a greater risk of and vulnerability to HIV, continue to hamper progress and threaten the gains made in the biomedical sphere of HIV prevention and treatment. In addition to women and girls’ biological susceptibility to HIV, women and girls face many interacting sociocultural, economic and legal challenges that worsen their vulnerability to and impacts of HIV.



9. Connecting strategic investment and women’s rights

Strategic investments need to look to long-term change that respects, protects and fulfills the rights of all

women and girls, across the life-cycle and in all of their diversity.

The end-users of medicines and services need to be able to make informed decisions so that having access to services means having the capacity and choice to use and benefit from them. There is a need for qualitative examination to ensure that gains in access to treatment are not achieved at the expense of women’s human rights or dignity.

“We have to document this work and then design a program – not only for continuing these dialogues, but also for programming for prevention in a way that is new and innovative and actually addresses some of these issues of power.”

Further, the realities of women’s lives must be addressed both in terms of immediate practical needs (HIV prevention, treatment, care and support) as well as longer term strategic interests, through the sustained work of shifting the unequal power relations between women and men.

With the increasing commitment to and focus on bio-medical responses to HIV, there is a renewed need to advocate for equal commitment to and focus on addressing the societal context perpetuating and maintaining HIV risks and vulnerabilities, especially for women and girls in all their diversity. Bio-medical responses need to be balanced with responses focusing on achieving gender equality, and ensuring human rights protections in all aspect of the HIV response.

The strategic investment approach has focused on directing resources to the areas where they are perceived to make the greatest impact. This has resulted in more concerted “targeting” of key populations (such as people who use drugs, sex workers and LGBTI communities). However, the language of risk and vulnerability can reinforce stereotypes and serve to marginalize the marginalized; manifesting existing barriers to access to services free of violence, coercion and discrimination.

At the same time, perceptions and constructions of “low risk” are translated into “no risk”, harking back to the early years of the epidemic, when women were all but excluded from the HIV response. Lesbian women, who have traditionally been invisible within the HIV response as being perceived to be at low risk for HIV acquisition and transmission, have been neglected not only in

relation to HIV services and information, but also within a broader context of sexual and reproductive health, safety and pleasure.

“If they are all so clear that we are not vulnerable, why are some of us [women who have sex with women] HIV positive and why do we get STIs? What do they know about our sexuality?”



10. Connecting donors and stakeholders re: strategic funding for women’s programs

Stakeholders at all levels need to organize to bring about longer-term political and societal shifts.

Three decades into the HIV epidemic there remains a lack of consensus on what an adequate and effective response to HIV looks like for women across their lifespans and in all of their diversity. 89% of women living with HIV are reporting gender-based violence as a lived reality* – an emergency that it is not being treated as such.

the women’s movement. Serious investment is needed over the short- and longer-term, as well as a review of mechanisms and a shift in the “rules” of how women access funding.

A critical next step will be to agree an analysis of the issues and develop a shared theory of change. Despite an emerging evidence base informing the connection between HIV and gender-based violence, many questions and gaps remain among donor governments and development agencies regarding what works to address these intersections, at the same time as HIV is being deprioritised in development agendas. Women and their communities need to have the capacity and skills to not only identify, but also respond to and monitor human rights violations when they occur, whilst programs need to go beyond addressing human rights in their breach, towards the full protection, enhancement and fulfillment of rights as entitlements.

“Key populations are creating their own minimum package. We need a minimum package for women (in all of our diversity). And not just PMTCT.”

This calls for a shift in both theoretical discourse and pragmatic thinking. There is a need for strategic coordination among donors and development agencies, as well as smart – funded – campaigning and advocacy from

* Salamander Trust (2014). *Building a safe house on firm ground: key findings from a global values and preferences survey regarding the sexual and reproductive health and human rights of women living with HIV*. WHO, Geneva. Available at: <http://salamandertrust.net/resources/BuildingASafeHouseOnFirmGroundFINALreport190115.pdf>

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All quotes in this document are from community workshop participants, country project leaders, or participants at the London stakeholder dialogue.