

Building *women's meaningful participation* in the scale-up of prevention of vertical transmission programmes

Ensure that women's voices are heard...¹

Most HIV infections in children occur in low- and middle-income countries, and more than 90 percent are the result of vertical transmission.² Approximately 1,000 babies acquire HIV every day during pregnancy, birth, or breastfeeding.³ 52% of all pregnant women living with HIV in low and middle-income countries did not receive anti-retroviral medication to prevent vertical transmission of HIV in the year 2010.⁴ Many countries still do not have sufficient services to reach women who need them and even where services are available, access and adherence to prevention of vertical transmission services remain weak.⁵ Yet, vertical transmission of HIV is preventable and constitutes a key strategy in effective HIV responses.

Setting the scene

It is possible to virtually eliminate vertical transmission and, in doing so, the '*Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping Their Mothers Alive*'⁶ (the Global Plan) is an important tool. The goal of the Global Plan is to reduce the numbers of new HIV infections among children by 90%, and to reduce the number of AIDS-related maternal death by 50% by 2015. Although covering all low and middle-income countries, the Global Plan prioritises the 22 countries⁷ estimated to have the highest number of women living with HIV. During the High Level Meeting on AIDS in June 2011, the goal of the Global Plan was taken to the highest level, with governments of the world committing to virtually eliminating vertical transmission and reducing maternal deaths.

The 2011 Political Declaration on HIV/AIDS, in conjunction with the Global Plan, provides an important framework towards ending new HIV infections among children by 2015, as well as toward the promotion and protection of the rights and health of women. The Global Plan does not seek to replace existing efforts, but rather to afford a framework which supports countries to assess their work, to cost what it would take to support pregnant women living with HIV and to stop new infections, to mobilise resources, to implement activities, and to monitor and evaluate these interventions.

Based on the recognition that current programme approaches have to be transformed, the Global Plan sets forth, as a first key principle for success, that women living with HIV are to be at the centre of the response, and that HIV responses are guided by a human rights framework⁸. It will thus be crucial to recognise and

respond to the gendered barriers, as experienced by women, in accessing prevention of vertical transmission programmes at a national level. At the same time, it is essential to listen and act upon the recommendations and interventions made by women to address these barriers.

In line with the above, the AIDS Legal Network (ALN), South Africa, in partnership with the Global Coalition on Women and AIDS (GCWA) undertook a virtual consultation on the Global Plan among women in the identified 22 priority countries in October 2011. The consultation was qualitative in nature, aiming to better understand women's realities and needs – as presented by women – with regards to prevention of vertical transmission initiatives. To facilitate participation of and engagement with women in the priority countries, women and their organisations from across the countries were actively involved in the virtual consultation, from the early stages of survey development, to gathering responses, analysing the data and collating the findings and key messages. In addition, a diversity of networks of women living with and affected by HIV, and women's rights advocates from the sexual and reproductive health and rights movement, acted as focal points at a national and/or regional level throughout the process.⁹

Nearly 300 women participated in the consultation, with special efforts made to reach out to women who did not have access to the internet. Thus, in some of the countries, the survey was administered in-person and the responses later entered into the on-line system

This briefing paper presents the key gender barriers and related recommendations, which women themselves have identified and voiced throughout the consultation.

Key barriers to women's access to prevention of vertical transmission programmes

Guided by national policies, prevention of vertical transmission programmes are available in all the priority countries.¹¹ However, the identified gap between policy development and its implementation, challenging the effectiveness of national HIV responses is also applicable to prevention of vertical transmission of HIV.¹²

Although specific challenges for the adequate implementation of prevention of vertical transmission programmes may differ by country and context, many of the challenges appear to be similar across the priority countries.¹³ While the Global Plan refers to structural barriers, including a wide range of social, cultural and economic factors that impact on women's access to and adequacy of prevention of vertical transmission services¹⁴, the gender-specific barriers to these services are not explored in detail. As such, it is relevant to consider women's views on and experiences with prevention of vertical transmission programmes, and identify the gender-related barriers that may affect their ability to make use of such services.

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It is clear from the responses that the unequal context of society, where women and men are treated differently and have different opportunities, greatly impact on the extent to which

for analysis.¹⁰ Women who participated in the survey are between the ages of 18 and 50 years old. Almost half of the women participating also indicated that they personally have sought out or accessed prevention of vertical transmission services in their country.

women are in the position to make informed sexual and reproductive health choices; to access healthcare services; and to ultimately benefit from available HIV prevention, treatment, care and support programmes and interventions. Moreover, socio-cultural and

religious values and norms are as much key to women's risks and vulnerabilities, as they are additional barriers for women's access to prevention of vertical transmission programmes.¹⁵ The following section outlines such barriers, following the themes that emerged from the findings of the virtual consultation.

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STIGMA AND DISCRIMINATION

Stigma and discrimination of women living with HIV, by communities, healthcare workers and women's families, were highlighted by women as key barriers to service utilization. In cases where women did not know their HIV status, they indicated that fear for stigma and discrimination led them to not want to get tested. Moreover, women openly living with HIV, reported experiencing stigma and discrimination in the form of judgements, because they were having children, and because they were seen as carriers of HIV that would then spread.

...women are still not accorded their rightful status when approaching clinics, since they are judged and subjected to many unfriendly clinics and health workers... [Swaziland]

Women also reported that the fear that these judgements could be extended to legal sanctions in cases where criminalisation of HIV has been established by law, make them refrain from seeking services.¹⁶ In some cases, women noted that given the degree of stigma and discrimination they risked experiencing from healthcare providers, they turned instead to traditional birth attendants. Alternatively, women would chose to attend antenatal services without disclosing their HIV status, in order to not expose themselves to mistreatment, humiliation and discrimination.

In many instances, women living with HIV encountered ill-treatment by healthcare providers, in the form of derogatory communication and mockery.

As a woman from Botswana said:

...the discrimination and punishment of women living with HIV for having children make us then not to want to use services, because the risk is too high... [Botswana]

Even in situations where women have made use of prevention of vertical transmission programmes, some reported feeling pressured into breast-feeding their children, due to the high degree of stigma that would surround them, should they choose not to do so.

ABANDONMENT, ABUSE AND VIOLENCE

A common theme throughout the reports was the fear of abandonment, abuse and violence, and/or their actual occurrence, serving as significant barriers to women's access to prevention of vertical transmission services. The reports specifically highlighted that women were often the first member of the household to discover their status, through antenatal testing, and that this could result in them being blamed for bringing HIV into the household. Alongside with this blame, women reported experiencing abandonment, abuse and violence by partners, family, friends and/or the community at large. As a result, some women would abstain from accessing services and/or testing for HIV, or only do so at a late stage in their pregnancy.

Respondents also noted that violence often existed in the relationship prior to accessing the services and, as

such, engaging with the services represented a risk of this augmenting. As a woman from South Africa said:

...if you are in an abusive relationship, the woman will be scared to access the services, because she is scared of her partner... [South Africa]

The consequences of accessing prevention of vertical transmission services could be severe. Women reported that they may be forced to leave their homes; shunned by their partners, families and/or communities; or be

or even stop their wives/partners accessing information and services.

While most partners were not willing to be engaged, some women highlighted that in some societies it would be seen as inappropriate to access services without their partner's involvement, thus limiting their access. This was exemplified by reports that healthcare workers would sometimes ask where the woman's husband was before providing treatment.

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Family dynamics, in particular the opinion of the mother-in-law, would further compromise access to services. Without the support and engagement of their partners, respondents shared that they were unable to take part in prevention of vertical transmission programmes or that their involvement became more challenging, because of these family

subjected to violence by their partners. As a woman from Botswana said, a key barrier to women's access to prevention of vertical transmission services is:

...the discrimination that we face and the judgement, sometimes violence from our families... [Botswana]

MALE INVOLVEMENT

Respondents also indicated that men may not support their partners to go to antenatal clinics and participate in prevention of vertical transmission programmes, because of societal norms and practices in particular those surrounding pregnancy and delivery. Women reported that - as part of the cultural norms - they were expected to be subservient and humble, because they were women. In cases where a woman's partner did not want her to take part of these services, she was expected to conform. Also, male partners would sometimes see pregnancy and related healthcare as a 'woman's issue', and would thus refuse to be involved or participate in prevention services,

dynamics. Women also indicated that these prevention programmes neither tended to facilitate the engagement and support of their male partners, nor address hierarchies within families.

As a woman from Mozambique said:

...some women don't do it (access prevention of vertical transmission services) because they are afraid of their husband... [Mozambique]

In line with this, a respondent from Uganda called for greater awareness raising efforts, stating that:

...(countries) should sensitise their fellow women and husbands and support them to take on the programme... [Uganda]

ECONOMIC DEPENDENCE

Poverty and economic dependence were highlighted as additional factors hindering access to services, further aggravating women's dependency on the approval from

their partners and/or his relatives whether or not and when to access services. Provision of free services did not offer relief, as women still had to manage the costs related to travel, medication and formula, amongst others. Also, the time needed for accessing these services often involved negotiations with their partners, and thus added barriers to women's ability to access prevention of vertical transmission services.

In cases where the household money is controlled by the male partner, these challenges may be more intense, as women reported not being in the position to access the necessary funds, unless they could obtain it from their husbands. At the same time, even in cases where funds are not controlled by male partners or there is no partner present, women are often experiencing levels of poverty that leave them with impossible choices: food or medication. As a woman from Zimbabwe said:

...Competing priorities for use of limited funds in both urban and rural areas to cover associated antenatal costs and transport costs to health facilities. With the economic meltdown and inequalities, women are left at a disadvantage. Many, especially those in female-headed households struggle to make ends meet...
[Zimbabwe]

COMPREHENSIVE PREVENTION OF VERTICAL TRANSMISSION SERVICES

Women underlined the challenges of HIV and sexual and reproductive health services being located in different places, as this added to the burden of travelling to different locations and also increased the time and resources needed to access services. Moreover, women noted that prevention of vertical transmission services appeared to be only focusing on avoiding HIV transmission to the infant, without taking care of the women's HIV-related or overall health needs.

As such, there would not only be a lack of care and support for the woman during the delivery process, but also lack of support for the woman to care for their infants after child birth. Women particularly underscored challenges around continued access to treatment to sustain their health, as well as a limited ability to access formula to feed their infants. As a woman from South Africa said:

...women are not featuring enough as women in programmes and interventions...women as mothers are only seen as the bearers of children who have to prevent transmission to the child...
[South Africa]

...women are often experiencing levels of poverty that leave them with impossible choices: food or medication...

ACCESS IN RURAL AND REMOTE AREAS

Rural women highlighted the challenges faced in accessing services nearby their homes. They shared that it was difficult for women – time and money-wise – to undertake multiple trips to areas where services do exist, and that this obviously would affect the levels of service utilization.

Even in situations where prevention of vertical transmission services are available in rural and remote areas, women reported that healthcare workers were not in the position to adequately care for the significant number of women who needed these services, due to shortage of personnel. Women also underscored that many times available healthcare workers were not trained or sensitised to provide prevention of vertical transmission services without stigma and discrimination, thus adding to service utilization barriers.

In addition, respondents pointed out that women residing in rural areas were hardly reached by HIV education and awareness programmes, and often not informed about the possibility to prevent their child from acquiring HIV.

As a woman from Lesotho said, prevention of vertical transmission programmes are not equally accessible as:

...I am staying in one of the rural areas of my country and not even once have I ever heard of people coming to launch any of these programmes... [Lesotho]

MEANINGFUL PARTICIPATION OF WOMEN LIVING WITH HIV

One of the four key principles for success of the Global Plan is that women living with HIV are to be at the centre of the response.¹⁷ Yet, women identified the lack of their meaningful involvement as a barrier to the effective implementation of prevention of vertical transmission programmes. This was noted at all levels, from the development of plans and programmes, to the implementation and monitoring and evaluation.

While some women reported having been asked to participate and asked for their recommendations, they noted that there remained a gap in terms of their recommendations being truly listened to and acted upon.

As a woman from Uganda said:

...I strongly believe that change can be effected, but there is the need to meaningfully involve those who have gone through/are going through the experience... [Uganda]

Recommendations for Action

Based on the above findings, seven key recommendations for action emerge:

- 1. Include anti-stigma and discrimination campaigns and awareness raising as an integral part of the roll-out of prevention of vertical transmission programmes**
- 2. Strengthen social and legal systems to support women who fear or experience abandonment, abuse and/or violence**
- 3. Ensure that prevention of vertical transmission programmes strive not only to avoid HIV transmission to infants, but also ensure optimal health of women, while upholding and protecting women's rights**
- 4. Work with partners to address cultural barriers, including norms around masculinities and womanhood, so as to increase women's empowerment and strengthen male partners' support and engagement with prevention of vertical transmission programmes**
- 5. Link prevention of vertical transmission programmes to women's economic empowerment initiatives**
- 6. Evaluate the need for increased availability of prevention of vertical transmission services in rural and remote areas and determine ways to better enable women in these areas to access services**
- 7. Reach out to and meaningfully engage women living with HIV at all levels of prevention of vertical transmission programmes**

Conclusion

The findings of this virtual consultation reveal that there are serious gender barriers to women's access to comprehensive services to prevent vertical transmission of HIV. While virtually eliminating vertical transmission and saving mothers' lives is possible, doing so requires placing women living with HIV at the centre of the response and jointly taking action to overcome each of these gender barriers.

Women's voices and key messages gathered with this virtual consultation reaffirmed that women are eager and ready to engage in all processes affecting their lives, to have their voices listened to and acted upon. Women seek to be consulted and asked about their realities and needs, to be meaningfully involved in all stages, and to be truly placed at the centre of the development and implementation of prevention of vertical transmission plans at the national and global level.

Effectively responding to the challenges which lie ahead require meaningfully involving women living with HIV at every level, from the community, to national, regional and global levels. It will require engagement by the state and civil society, but also by communities and families, which can have a tremendous influence on how women and girls, as well as men and boys, perceive themselves and each other in society. It will be key to take forward a shared message which clearly underscores that gender equality, just as vertical transmission of HIV, benefits everyone.

Only in this way will it be possible to reach the goal and fulfil the commitment of virtually eliminating vertical transmission and decreasing maternal deaths.

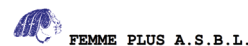
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4. GLOBAL HIV/AIDS RESPONSE: Epidemic update and health sector progress towards Universal Access, Progress Report 2011 (WHO, UNICEF, UNAIDS), p.154.
5. Stringer et al (2008) found that only half (49%) of all women living with HIV that accessed ANC services adhered to the full course of vertical transmission treatment.
6. The Global Plan can be accessed on www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110609_JC2137_Global-Plan-Elimination-HIV-Children_en.pdf.
7. The 22 priority countries identified in the Global Plan are: Angola, Botswana, Burundi, Cameroon, Chad, Cote d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Swaziland, Uganda, United Republic of Tanzania, Zambia and Zimbabwe.
8. Global Plan, p8.
9. This initiative would not have been possible without the collaboration, expertise, support and assistance from women and their organisations across the priority countries. We would like to acknowledge and express our thanks to ICW East Africa, ICW Southern Africa, ICW West & Central Africa, ICW Asia Pacific, Swaziland Positive Living (SWAPOL), Femme Plus A.S.B.L. (Democratic Republic of Congo), Kenya Network of Women with AIDS, National Network of Positive Women Ethiopians, Coalition of Women Living with HIV/AIDS (Malawi), Tanzania Network of Women Living with HIV, Society of Women and AIDS (Ghana), Muleide (Mozambique), Her Rights Initiative (South Africa), Namibian Women's Health Network, and AIDS & Rights Alliance for Southern Africa (ARASA).
10. These countries include Democratic Republic of Congo, Lesotho, Mozambique, Namibia, South Africa and Zimbabwe.
11. UNICEF. 2010. 'Preventing Mother-to-Child Transmission (PMTCT) of HIV: Fact sheets on the status on national PMTCT responses in the most affected countries'. [www.unicef.org/aids/index_preventionyoung.html]
12. UNAIDS. 2010 Report on the Global AIDS Epidemic.
13. Global Plan, p24.
14. Global Plan, p10.
15. Global Plan, p8. See also UNAIDS. 2010. UNAIDS Action Framework: Addressing women, girls, gender equality and HIV.
16. Of the 22 priority countries, Ghana, Namibia, Nigeria and South Africa are the only countries which do not have laws in place that criminalise HIV transmission or exposure, or are in the process of drafting such legislation. [www.gnpplus.net/criminalisation/index.php?option=com_content&task=view&id=12&Itemid=34]
17. Global Plan, p8.

...women identified the lack of their meaningful involvement as a barrier to the effective implementation...

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