Vital Voices:

Recommendations from consultations with people living with HIV on the IATT's Strategic Framework for PMTCT Components 1 and 2

International Community of Women Living with HIV
Global Network of People Living with HIV

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1. Executive Summary

Background

In response to insufficient recognition, commitment, or programming support for PMTCT Components 1 and 2, the Interagency Task Team (IATT) for Prevention of HIV Infection in Pregnant Women, Mothers, and their Children developed a *Draft Strategic Framework (2010-2015) for Primary Prevention of HIV and the Prevention of Unintended Pregnancies in Women Living with HIV in the Context of PMTCT* (Draft Strategic Framework). The IATT invited the International Community of Women Living with HIV Global (ICW Global) and the Global Network of People Living with HIV (GNP+) to review the Draft Strategic Framework and provide recommendations for strengthening the document.

Methods

Over a period of three months, ICW Global and GNP+ conducted consultations to solicit perspectives and personal experiences from people living with HIV to inform the revision of the Draft Strategic Framework. This process adopted a mixed method approach combining qualitative and quantitative feedback methods: a moderated online consultation among individuals living with HIV (66 participants from 16 countries); three facilitated focus group discussions (27 men and women living with HIV in Jamaica); an e-survey for people living with and affected by HIV (591 respondents from 58 countries); and, an expert panel to discuss the content and accessibility of the framework.

Findings

The consultations revealed that greater uptake of PMTCT services is facilitated by the following: the decentralization of services to communities; the provision of accurate information, in a non-judgmental and supportive manner to people living with HIV and their partners; the recognition of individual rights when testing for HIV; the presence of peer support as part of post-test counseling and PMTCT programming; the education of healthcare providers on the rights of individuals accessing services; and the responsible use of language on sexual and reproductive health.

Recommendations

The majority of key messages and recommendations emerging from the consultations resonated with those articulated in the Draft Strategic Framework. ICW Global and GNP+ recommend the integration of the consultation findings to the final Strategic Framework. This will significantly improve the quality and accessibility of the document and ultimately increase the uptake of comprehensive PMTCT services.

2. Introduction

In 2007, the WHO and UNICEF, with the Interagency Task Team (IATT) for Prevention of HIV Infection in Pregnant Women, Mothers, and their Children, released a Guidance on the Global Scale-Up of the Prevention of Mother to Child Transmission (WHO 2007) (Global Guidance). The Global Guidance supports the implementation of all four components of the United Nations comprehensive approach to the prevention of mother to child transmission of HIV (PMTCT): (1) primary prevention of HIV among women of childbearing age; (2) prevention of unintended pregnancies among women living with HIV; (3) preventing HIV transmission from a woman living with HIV to her infant; and, (4) providing appropriate treatment, care and support to women living with HIV and their children and their families.

Although the Global Guidance included all four components of comprehensive PMTCT,[1] implementation has been skewed with components three and four receiving greater emphasis and demonstrating significant progress while components one and two (primary prevention of HIV infection among women of childbearing age and prevention of unintended pregnancies among women living with HIV) have not benefited from the same level of recognition, commitment, or programming support as the other two components.

In response, the IATT drafted a strategic framework on the first two components of PMTCT and, in its near-final stage, invited the International Community of Women Living with HIV Global (ICW Global) and the Global Network of People Living with HIV (GNP+) to provide comment and feedback.

ICW Global and GNP+ conducted consultations to solicit perspectives and personal experiences from people living with HIV to inform the *Draft Strategic Framework (2010-2015) for Primary Prevention of HIV and the Prevention of Unintended Pregnancies in Women Living with HIV in the Context of PMTCT* (Draft Strategic Framework).

This report describes the methods used to document the perspectives of people living with HIV and presents recommendations by people living with HIV on how to strengthen the Draft Strategic Framework. The recommendations are based on and have been substantiated with findings from the consultations.

[1] Various documents use the terms 'prongs', 'elements', and 'pillars' instead of 'components' when referring to comprehensive PMTCT.

3. Methods

In early December 2010, ICW Global and GNP+ began a collaborative consultative process among people living with HIV on the current draft of the Strategic Framework. The aim of the consultations was to facilitate the meaningful involvement of people living with and affected by HIV into the final version of the document and to ultimately strengthen the document through the community's unique perspectives and insights into this area of HIV prevention. This process adopted a mixed method approach including the following:

- A moderated online consultation among individuals living with HIV. Sixty-six participants from 16 countries engaged in the online consultation (29 November – 20 December 2010);
- Three facilitated focus group discussions among 27 men and women living with HIV in Jamaica (15 January 2011);
- An extensive e-survey for people living with and affected by HIV. The e-survey was completed by 591 respondents from 58 countries (11 January – 28 January 2011);
- An expert panel (i.e. a conference call among experts) in the PMTCT field to discuss the framework. These experts included individuals living with HIV, service providers, advocates, academics, and our partners within the UN system (24 January 2011).

Each of these assessments yielded different types of data, with different strengths and limitations, but similar results in key areas. The underlying reports are attached as appendices to this final report.

The next section of this report presents recommendations by people living with HIV on how to strengthen the Draft Strategic Framework. The recommendations are based on and have been substantiated with findings from the consultations.

4. Recommendations

This report recommends the following:

- the framework be restructured for greater clarity and accessibility;
- the introduction and other sections be grounded in the realities of people living with HIV;
- the purpose of the Strategic should be clarified and reinforced;
- within the Guiding Principles sections, the need for greater inclusion of people living with HIV in all decision making bodies, the role of gender-based violence in primary prevention and in the prevention of unintended pregnancies among women living with HIV, and the need for the reduction of stigma and discrimination as a necessary precursor to successful prevention interventions should each be reinforced;
- the section on key strategies and actions be augmented with the specific findings contained in this report;
- the service delivery and entry points should be disaggregated for the ease of the reader;
- supportive HIV testing and counseling and the need for an integrated package of service, quality counseling, and support for safe conception should be emphasised within the services and components 1 and 2; and
- the need for policy makers and program implementers to be responsible in their choice of language around PMTCT and avoid moralistic language that may increase the both the risk of harmful stigma and discrimination from health care workers, partners, and other third parties, and harmful self-stigmatization among women living with HIV and other key populations.

The rest of this report offers a rational and suggestions to substantiate each of the recommendations based on findings of the consultations with people living with HIV.

3.1 Re-structure the Strategic Framework

The overarching feedback on the document from the communities consulted revealed both the urgent need for such a framework and the need for structural revision to ensure the document itself is easy to use by its intended audience. The structure of the document proved difficult for some participants, often obfuscating the substance of the document. This was particularly articulated on the expert teleconference by service providers,

networks of people living with HIV and other partners who would be using the document to guide the delivery of services for Components 1 and 2. TThe most basic recommendation, therefore, is a simpler structure, for which we propose the following as a table of contents:

PROPOSED REVISED TABLE OF CONTENTS

1. Introduction
2. Purpose of the Strategic Framework
3. Intended Audience
4. Guiding Principles
5. Key Strategies and Actions:
   - **Strategy 1**: Link SRH and HIV at the policy, systems and service delivery levels to ensure coordination for PMTCT components 1 and 2 at national and district levels
   - **Strategy 2**: Strengthen community engagement and community-based delivery of integrated SRH and PMTCT services
   - **Strategy 3**: Promote greater involvement of men in MCH/STI/FP services
   - **Strategy 4**: Engage organizations of people living with HIV (PLHIV) in the development and implementation of PMTCT policies and programmes
   - **Strategy 5**: Ensure non-discriminatory service provision in stigma-free settings
6. Service Delivery Settings and Entry Points
7. Primary Prevention of HIV
   - 7.1.1. Essential Services
   - 7.1.2. Components of the Service Packages
8. Prevention of Unintended Pregnancies
   - 8.1.1. Essential Services
   - 8.1.2. Components of the Service Packages
9. Goals and Targets
10. Supporting Programming and Policy Guidance
11. Appendix 1: Strategic Framework Development Background
12. Appendix 2: References and Tools

The proposed structure has several advantages over the current version. In its current position, the section on Supporting and Policy Guidance immediately follows the Guiding Principles and precedes all other substantive sections. This shifts the focus away from components 1 and 2 to all four components of PMTCT. The reader is already aware of the

context of the four components because this is mentioned in the introduction. (See below for recommendations regarding increased clarity on the relationship between the Global Guidance (comprehensive) and the Strategic Framework (focus on prongs 1 and 1) in the Introduction section).

Also to enhance clarity, it would be useful to re-organise the essential services and the components sections so that the essential services for the primary prevention of HIV is followed by the components section, and the essential services for the prevention of unintended pregnancies is followed by the relevant components section. Components 1 and 2 represent distinct areas of work, each requiring analysis and action. The proposed format would help clarify the services and components under each component of PMTCT, thus making the document more accessible to the reader.

Having addressed the overarching structural concern, this report shall turn to the substantive feedback for each of the Draft Strategic Frameworks' sections.

3.2 Ground the Introduction in the realities of people living with HIV

The introduction to the Strategic Framework must start with the voices of people living with and affected by HIV. This framework does not suggest new work. It pulls together good practice and highlights important links between programmes in order to respond to the needs of individuals accessing PMTCT services and to maximize the success of such programmes. The consultations revealed examples of the realities of those who will benefit from more efficient and responsive services; and ICW Global and GNP+ recommend that these voices are articulated in the Strategic Framework. The following is an example to set the context for the need to address components 1 and 2:

"I think for some of us, when we find out that we are positive we kind of give up that right as well. We say we don't want no more man, we won't have sex, we won't have children, but once we start going to workshops and you start getting all the information and you start understanding about your status then you start changing your mind and knowing that yes I have the right to this and I have the right to have sex and the right to have another child and the right to have a child. So I guess sometimes it starts with us as well," – **female respondent, focus group discussion, January 2011, Jamaica**

In addition, there are two textboxes in the introduction from the Global Guidance: one summarizing the essential services for maternal care for all women, regardless of status, and the other summarizing an additional package of maternal care services for women

living with HIV. On the expert teleconference, one participant mentioned that these are confusing in the introduction as the document later puts forth services and components for components 1 and 2 specifically. Additionally, there is no text explaining how these packages are related to the Strategic Framework, which elaborates on many of the essential services identified in the Global Guidance. As stakeholders are expected to reference both documents, a better explanation of the relationship, without the bulky textboxes, is preferable.

3.3 Clarify and reinforce the *Purpose of the Strategic Framework*

This section should clarify that the Strategic Framework is an initiative, led by the IATT, designed to meet the needs of government, policy makers, donors, non-governmental organizations, networks of people living with HIV, HIV programme managers, healthcare providers and other HIV advocates supporting HIV prevention amongst women of child-bearing age and unintended pregnancies amongst women living with HIV.

This section should then proceed to reinforce the need for the Strategic Framework. Across all four types of consultations, people living with HIV and experts in the field of PMTCT worldwide agreed that the first two components of PMTCT have received minimal attention in global PMTCT efforts. They supported the IATT's effort to create a useful document in order to enable service providers, governments, and other stakeholders to implement rights-based programs and policies rapidly and successfully. This framework and its rights based approach are particularly important given the lack of response towards the sexual and reproductive health rights of women living with HIV. Coercive sterilizations, abortions, lack of family planning options, almost uniform world-wide stigmatization of a woman who is HIV-positive choosing to become a mother, and other rights violations are already widespread and often justified in the name of protecting future generations. In the absence of a strong framework on how to achieve PMTCT goals while respecting and promoting the rights of people living with HIV, potential PMTCT scale-up risks increasing opportunities for these abuses as well.

3.4 Clarify the *Intended Audience*

The final document should more clearly articulate the intended audience. Consultations with people living with HIV revealed a broad range of actors in delivering PMTCT services. In the current draft version, it states that the document is aimed at global, regional and national partners working in SRH and HIV, and then mentions 'National' policy makers and

'District' programme managers. Also, the list does not include governments and donors, who play an instrumental role in supporting the integration and strengthening of services. Finally, the term 'community partners' is quite broad and should be defined to include non-government organizations, organizations and networks of people living with HIV and other HIV advocates.

PROPOSED LIST OF INTENDED AUDIENCE
Global, regional and national partners working in SRH and HIV, including:

- Governments
- Policymakers
- Donors
- Non-governmental organizations
- Organisations and networks of people living with HIV
- HIV programme managers
- Health care providers
- HIV advocates, including women's organizations and key population groups

3.5 Emphasise the *Guiding Principles*

Consultations with people living with HIV highlight the importance of emphasizing three of the guiding principles in this document. The first is the **GIPA principle**. Several of the respondents in the online consultation expressed the importance of involving the views of people living with HIV in the development of guidance related to the issues affecting them. This guiding principle can be further developed by adding that people living with HIV have significant knowledge, experience and insight into the issues that are important for them and for responding to the epidemic effectively. Therefore, if the HIV prevention needs of people living with and affected by HIV are to be adequately addressed, they must be meaningfully involved in all aspects of policies and programmes that impact them.

The second principle to emphasise is the **reduction of stigma and discrimination**. Several of the respondents in the online consultation are advocates who are living with HIV and they discussed the need for protective laws that ensure non-discrimination, reduce stigma, provide access to justice and change harmful gender norms to address the underlying causes of primary infection of women and the prevention of unintended pregnancies among women living with HIV. Participants in the consultation, survey, focus groups, and expert teleconference also agreed on the importance of programmes that promote education and create the conditions for people living with HIV and their partners

to be free to make informed choices about their sexual and reproductive health, including regarding whether and how to be sexually active and fulfilled and whether and how to conceive and enjoy a family. Such policies and programmes enable people living with HIV to protect and care for themselves and others.

Finally, within the broad guiding principle "Human Rights and Gender," the need to address **gender-based violence** should be emphasized more strongly. Participants in the online consultation discussed rampant gender based violence in their countries and agreed that few accessible prevention and impact mitigation programs existed to address the violence. Participants in the online consultation, survey, and focus groups revealed that that the threat of violence is a barrier to successful PMTCT interventions on several levels. Fear of violence prevents women from disclosing their status to partners or accessing voluntary testing and counseling and family planning. Women who fear violence are less able to exert control over their fertility, negotiate safe sex or condom use, or confront marital infidelity, all of which inhibit primary prevention efforts. In addition, women who know their status and fear disclosure cannot ask for partner support to successfully complete a full PMTCT programme, they are less likely to adhere to drugs for fear of discovery, and are more likely to resort to mixed feeding practices to avoid discovery as well. There are also the clear links between gender-based violence and poorer health outcomes for both mother and child as a result of physical and mental trauma.

3.6 Strengthening the Key Strategies and Actions

The strategies are quite comprehensive in their scope, which was reflected in participant reactions across the consultative process. These five strategies, when pursued in conjunction with each other and in line with the Strategic Framework's Guiding Principles, should be effective in increasing the role primary prevention and prevention of unintended pregnancies play in the global scale up of PMTCT. In turn, they contribute to the greater health and well-being of women and families worldwide. Before considering each strategy separately, the following are brief, general recommendations to strengthen and make more accessible this vital section.

First, before the 'Background' section of each strategy, the Framework should include a brief quote to illustrate the voices of women and individuals who would benefit from the services. After or within each 'background' section, it should include a section on 'Challenges in implementation' (before 'Recommendations') that will give the reader some context for the strategy.. Finally, under 'Recommended key actions', the Strategic Framework should state *who* should carry out the policy, systems, and service delivery actions so that it is clear to whom the specific recommendations are directed.

***Strategy 1**: Link SRH and HIV at the policy, systems and service delivery levels to ensure coordination for PMTCT components 1 and 2 at national and district levels*

"Less than 90 per cent of the female participants [in the focus group discussions] were able to explain the PMTCT process as it is rolled out in Jamaica. There was general confusion about the basic minimum package of care under the programme and so participants' experiences varied. What was clearly established was that all the mothers were tested for HIV, although only limited counseling occurred. After the testing, it became unclear what the process involved." **- Focus Group Discussion Final Report, January 2011, Jamaica.**

Better coordination of a rights-based approach to SRH and HIV at all levels is important throughout the world and will hopefully address the many inconsistencies among SRH and HIV programmes. For example, the focus group discussions revealed that even where a national PMTCT protocol calling for integration of SRH and HIV services exists, there is incredible inconsistency in the use of that protocol. Various clinics and hospitals follow different protocols when implementing PMTCT programmes, yielding even greater confusion among people living with HIV and their partners over what constitutes comprehensive PMTCT. These inconsistencies range from when ARVs are administered to women and babies to prevent transmission, or the length of time the mothers living with HIV receive breast milk substitute, to the level and quality of counseling that takes place and facility staff's knowledge of the actual programme.

Attitudes of health care workers towards women who are at risk of HIV or who are living with HIV also vary greatly among different facilities and coordination efforts must ensure that in addition to understanding SRH and HIV services, health care workers and stakeholders understand SRH rights and other important health rights, such as the right to confidentiality. Indeed, the consultation showed that worldwide, the right to confidentiality in health care has been the most consistently and perniciously violated, often with impunity.

***Strategy 2**: Strengthen community engagement and community-based delivery of integrated SRH and PMTCT services*

"The day I was tested, I was with my husband and we became HIV discordant. I was positive and he was negative. When we were told, to be given back the results, it was as if the health care worker did not have enough time for us. She was like, do you know what discordancy is? I said yeah, then they tell the husband, because he didn't know. And she said you are negative, you are positive. May I have another couple? They didn't give us enough time, which resulted the husband to leave me at the health facility, abandon me there, up to now. So I had to give birth minus him. Then when it was time to give birth, the doctor told me that one I was to be

operated, I shouldn't have the labor pains, then two that I was supposed stop on that baby. And I tell you I was sterilized, because I didn't have the choice and I wasn't made to sign anywhere. I just found myself like that. And recently I had to go for scan, that was when I found out I was sterilized. I was sterilized on October 23, 2005. I found out last year - 2010." **– female interviewee from Eastern Uganda, ICW Global Video Interviews, 9 March 2011.[2]**

Strategy 2's emphasis on community engagement and community-based service delivery was welcomed across the consultations. The majority of participants in the online survey (70%) stated that health worker attitude was one of the factors affecting accessibility to services. This was followed closely by financial problems (65%), transportation problems (58%), and long waiting hours (55%). Each of these problems may be addressed by this strategy, although health care workers' attitude change is addressed most directly in key strategy 5 on stigma and discrimination. Health care workers are members of the community, and seeking to strengthen the community's understanding and engagement in integrated SRH and PMTCT services will affect their own understanding of the role they play in delivering these services. Voluntary counseling and testing (VCT) services that were offered in community settings, as opposed to those which require individuals access health facilities, have shown remarkable increased uptake of VCT services. In addition, community based services are more accessible, requiring less travel and fewer hours devoted. In such settings, it is even more important that the right to keep one's sero-status, or other health-related information completely confidential, such as a desire to use a form of birth control, must be respected and ingrained into both the healthcare culture and in the culture of the community.

The focus group discussions revealed a gap in participants' knowledge and understanding of PMTCT programming, even though at least 75 % of the women participating had accessed some form of PMTCT or family planning services. This had resulted in situations where women were unable to demand the services they required or to ensure that services

[2] ICW Global conducted video interviews of women living with HIV from sub-Saharan Africa who participated in a four day advocacy training from 6 March 2011 - 9 March 2011. The training was co-hosted by UNAIDS, the Center for Health and Gender Equity (CHANGE), and the Positive Women's Network (PWN). The women were asked to define sexual and reproductive health, to explain whether women living with HIV had a higher risk of experiencing a violation of their right to enjoy sexual and reproductive health, and to share whether they had ever experienced such a violation. The questions were deliberately open-ended. The videos themselves are available upon written request but due to privacy concerns, the links are not included within this report and the women's names are withheld as well.

being provided were the best available. Community engagement, therefore, must include widespread dissemination of information on SRH, including family planning and HIV and other STI risk, and human rights as well as PMTCT services specifically. When the community is informed, people can assert their own rights and invest in their own health care.

Participants in each of the four consultations consistently stated that peer support is key for women who learn that they are HIV-positive. It is particularly traumatic for women to learn their status during pregnancy as they struggle with the diagnosis itself, disclosure to their partners, whether to continue the pregnancy, amongst other complicated and confusing issues. Women want to engage with women who have been in the same position and who can help them better access services and uptake available options. Angelina Namia, who currently manages the *From Pregnancy to Baby and Beyond* Project at Positively UK (www.positivelyuk.org) and participated in the expert conference on the Strategic Framework, discussed the vast improvement in outcomes for mothers living with HIV when linked with other positive women who had been trained as peer mothers to provide emotional support and also to provide practical support to access services and take control of their health and well-being. Women living with HIV who participated in the survey, consultation, and focus groups consistently cited importance of peer support to them as they accepted their diagnosis and accessed services.

The survey, focus groups, and expert teleconference, however, revealed a noticeable gap in peer support for men. Male participants in the focus group felt they had no support to learn about their own sexual and reproductive health or to engage with their partners in PMTCT services. This problem was also cited by men in the e survey as a barrier to increased male involvement in PMTCT. During the expert teleconference, Ezekiel Kodonde, from Women Fighting AIDS in Kenya (WOFAK) discussed his work with couples in PMTCT settings that has shown that men, and their families, benefit from having male mentors within antenatal facilities. Programmes such as the Male Plus PMTCT Champions, led by WOFAK, promote the engagement of the male partners of pregnant women in PMTCT settings and ensure that both parents are able to participate in making informed decisions about the health of their children and their family.

Strategy 2 is also the appropriate place to put greater emphasis on the role of community health providers, including traditional birth attendants. A key finding of the online consultation was that women in different communities throughout the world have shown reluctance to access hospitals and clinics, in preference for the traditional birth attendants with whom they are more comfortable. This reflects both the need for greater healthcare capacity to increase access and better education to eliminate rights violations in healthcare settings, such as the violation of the right to confidentiality and to access health care

services free of harmful discrimination. Resources must be allocated to ensure that traditional birth attendants are able to serve the needs of women who are living with HIV, including those who may not know their status, and their children. It is worth restating that the Strategic Framework's emphasis on nonjudgmental attitudes among service providers is vital from both a human rights perspective and a health outcomes perspective.

Strategy 3: *Promote greater involvement of men in MCH/STI/FP services*

"Men just can't get up and go want information. The woman has to let him know form the beginning." **- male respondent, focus group discussion, January 2011, Jamaica**

"When the woman gets pregnant and you go to tell the man, some of them get ignorant and you don't see them again. They blame it all on you and you don't know who to turn to…" **- - female respondent, focus group discussion, January 2011, Jamaica**

The survey, consultation, focus groups, and expert teleconference all reveal that male involvement in PMTCT is generally low. A majority of participants who cited low male involvement stated that men are often discouraged from participating in antenatal services in the public health sector. As a result, men who would want to participate in the PMTCT programme often do not get the opportunity to do so or are unsure how to engage. In addition to the general discouragement of male involvement in antenatal health care, a significant number of positive women who participated have not disclosed their status to their partners. Women who have not disclosed their status cannot seek their partners' involvement or support in ensuring their child is born and remains HIV-negative. Therefore, any effort to include men in PMTCT programmes must include support and counseling to help women disclose safely to partners. Where women fear losing their partners over their status, or suffering violence and other forms of discrimination based on their sero-status, there can be no partner involvement.

The consultation confirmed that there is a worldwide gap in reproductive health services and information available to men living with HIV, as well as for men who are in sero-discordant relationships with women living with HIV. The Strategic Framework should address the need for information on male SRH and HIV and the role of male parents in the health and well-being of their children. Both primary prevention of HIV among women and the prevention of unintended pregnancies among women living with HIV require some ability to negotiate sex with a partner. Without educating those partners on the health risks and benefits to safer sex and planned parenthood, women are put under enormous pressure to take single-handed responsibility for their own, their partners', and their families' health. In particular, there is too little counseling available for men who are in

sero-discordant relationships with women who are living with HIV and their needs should be considered within PMTCT programming.

Strategy 4: *Engage organizations of people living with HIV (PLHIV) in the development and implementation of PMTCT policies and programmes*

"I got home and was taking a nap before I reviewed the day when one of the pregnant women called. She said she wanted me to know she got home safely and how grateful she was to get the information … on her rights. Now she could take it to the clinic which had delayed delivering [her] baby because she refuse[d] to sign permission for tying her tube when they deliver the baby. She said that they explained she did not have sufficient amniotic fluid and should operate two weeks ago when the baby was 7 months old [sic]. It was put off when she refused to sign the permission. She said she sought the support of the social worker and was told she must follow the Doctor's order. I will be referring her to a counselor today and see how much support we can get for her to have all the information she needs to make the choice that will ensure both her and the baby's health." **– focus group facilitator, in an email to the consultation coordinators, sent from Jamaica on Monday, January 17, 2011 8:34 AM.**

Participants across the consultation stressed that peer counselors and support groups play a vital role in successful PMTCT programmes and in maximizing outcomes for families living with HIV. These individuals and groups do not function in isolation, but are linked to larger networks of people living with HIV who provide support and ensure that the realities on the ground are translated to stakeholders. Meaningfully engaging with the networks of people living with HIV from inception through implementation ensures that resources are not wasted because programmes are tailored to succeed based on the actual challenges to successful PMTCT on the ground. Engaging with and investing in the networks is the surest and most effective way to ensure accountability and the cornerstone of any rights-based approach to PMTCT. When multilateral institutions or international non-governmental organizations, or donor nations acting in concert with host nations, implement PMTCT policies without consulting local communities there is no direct way for those who receive these services to hold them accountable for their actions. At best, democratic nations receiving aid may be held accountable through their own country's democratic process. Networks of people living with HIV, however, are directly accountable to and acting on behalf of their constituents. Without their involvement, even the best of programs are tinged with paternalism.

In addition to working with networks of people living with HIV, policymakers and implementers should engage women's groups and networks of key populations to ensure

that the drive to increase testing for young women does not create an atmosphere of hostility and fear.

Strategy 5: *Ensure non-discriminatory service provision in stigma-free settings*

"Stigma kills." **- female interviewee from Ghana, ICW Global video interview, 6 March 2011, Washington, D.C.**

"I was born positive, I have never experienced negative life… When you are born positive, you are denied to have choice, you are denied to have a relationship of your own, you are denied to have sex, they think if you are positive, or born positive, you don't need, you should not fall in love, because you are infecting others even if you are protecting yourself. I think, most of the counselors should be given refresher courses because they are the first people who stigmatize people who are living positively. There was a day I came in, the lady told me What do you want? You people who have HIV, we are tired of you. It made me feel so bad, so neglected. Sometimes even the doctors themselves, when you are sick, admitted to the hospital, they neglect you. It has happened, I know of two people who have died. I cannot say the name, because I fear… I work in the same hospital so I fear to say the name. To be counseled by someone who is living with HIV, it is very good because he or she knows the pain. And, she will know how to handle you, and which type of words she should use and which type of words she should not use with you. She will not neglect you because if she feels like neglecting you, she will be neglecting herself as well… HIV is not something that makes people so vulnerable but stigma… let me say, stigma kills. I have stayed for 23 years now, but if I am stigmatized for one whole week, I will get completely down and I may die… Because I have hope, and I am very strong, I know I will not die of HIV. But the fact is, if stigma keeps on, we are losing a lot of lives because they will not have the strength to go to the hospital to get their drugs, they will not adhere, they will not come out, because they are stigmatizing them, they will not feel like they should come to the hospital or even disclose their status," **– female interviewee from Southern Sudan, ICW Global video interview, 9 March 2011, Washington, D.C.**

Worldwide, stigma and discrimination amongst health care workers continues to be a problem. One Jamaican focus group participant recalled going to a clinic and asking for condoms and being asked why she would need them since she already had HIV. She never asked again. Not only stigma and discrimination on the basis of HIV act as barriers, but also other cultural taboos around sex, reproductive health, or childbearing. For instance, in Jamaica and throughout much of the world, adolescents who become pregnant face severe

discrimination from their peers and society in general while an adolescent who is pregnant and positive faces double stigma. Adolescents also may face cultural taboos when seeking access basic family planning or reproductive health services and commodities. Some cultures severely disparage those who engage in commercial sex work or consensual sex outside of marriage. Cultural views of the relationship between parent and child or husband and wife may subject women and girls who seek SRH or HIV services without notifying a parent or husband to censure on the part of health care workers and may even result in coercive disclosure. Healthcare workers, in facilities and within communities, must be given training to recognize the signs of violence and to recognize the role that the threat of violence plays in women's decisions. Stigmatizing a woman who does not disclose her status to an abusive spouse leaves the woman more isolated and less likely to turn to the system for help dealing with either the violence or her health needs. Views on marital infidelity on the part of a wife may also keep women from accessing services or voluntarily taking an HIV test. Such high levels of stigma and discrimination around both SRH and HIV form by far the greatest barrier to the primary prevention of HIV and the prevention of unintended pregnancies among women living with HIV. Therefore, in addition to setting clear standards to break down harmful attitudes towards women living with HIV and key populations of women at risk of HIV, a proactive culture of tolerance and nonjudgmental attitudes among healthcare workers must be rigorously fostered.

3.7 Clarify Service Delivery Settings and Entry Points

Consultation participants highlighted a variety of settings where women can access HIV services, which form part of components 1 and 2. While the list of service delivery settings and entry points in the Strategic Framework is comprehensive, it is not clear where women and their partners receive HIV testing, where they receive counseling, and where they might be referred for treatment and support. A visual diagram would be useful in clarifying where PMTCT services are delivered for both HIV-negative and HIV-positive women. Added to this diagram could be a description of the services offered in each of the settings. This would be valuable for all stakeholders looking to grasp what is delivered as part of PMTCT efforts for components 1 and 2 in a range of settings. It would also enable stakeholders to better understand and more effectively monitor the continuum of care for women who are diagnosed with HIV and their families.

Missing from the list of settings where HIV testing is offered to women are: private practice clinics and accident and emergency centers.

Under 'priority entry points', the term 'community' should be amended to community-based facilities. In the e-survey, when asked where they would want to receive services for HIV and family planning if these were integrated, the majority of respondents (36%) indicated in HIV clinics and 32% in community-based facilities.

3.8 Emphasise supportive HIV testing and counseling as part of *Primary Prevention of HIV*

Essential services:

"Firstly, the ideal is to know your status BEFORE pregnancy...it is twice as traumatic to get the results when you are in the process of creating a life. However if that is the time you find out then your circumstances should be used to inform the counseling needs. Is there a partner that needs to know? What is the level of spousal/ family support? Is there risk of violence in disclosing? What social services will best help her/family? " – respondent, e-survey, January 2011

Participants in the consultations highlighted that in expanding testing settings for women, appropriate timing, testing venues and supportive counseling must be assured, especially among pregnant women. This section of the Strategic Framework must mention that the experience of testing while being pregnant and receiving an HIV positive diagnosis may have traumatic consequences for a woman and may affect her ability to seek services and support for herself and her child. Therefore, women should be offered an HIV test and should be supported to determine whether they want to take the test, when to take it, and to assert their rights to informed consent, confidentiality and freedom from coercion.

Equally important to highlight in this section is counseling support for women and their partners. Professional counseling must provide accurate and non-judgmental information and should be complemented with peer one-on-one counseling and group support. Participants in the e-consultation emphasized the importance of peer-to-peer counseling by HIV-positive women. Peer counselors should be engaged within health facilities wherever feasible and, at a bare minimum, providers must be able to link women with peer support groups in the community. Post-test counseling is important for women who test HIV-negative so that they understand their risk factors, in particular their heightened risk during pregnancy. In order to deliver quality counseling, appropriate training is essential for people living with HIV delivering peer-to-peer counseling and for health care providers.

Components of the Service Package for Primary Prevention:

The components listed in this section are comprehensive. However, the table would benefit from the following additions:

- The inclusion of men, key populations (including women who are sex workers or who use drugs), and adolescents and youth, in the 'target population' in the description of each of the components;
- The inclusion of counselling and testing for partners as part of the second component 'HIV testing and counselling for pregnant and post-partum women';
- The component on gender-based violence should include a risk assessment of a woman's environment to explore whether there are experiences of violence in her relationship.

3.9 Emphasise an 'integrated package of service', quality counseling and support for conception as part of the *Prevention of Unintended Pregnancies among Women Living with HIV*

Essential Services:

"There certainly seem to be a lot of reports of women being told they mustn't even have sex, let alone babies - so my question here is "who is deciding that these pregnancies are unintended - and if it is indeed the women, are they having access to fully informed consent? There are, of course, other important issues here, if that IS the case - namely are they receiving good access to contraceptive services or are these dependent upon them being) married or be having their husband's consent?? And if there is still a pregnancy despite contraceptives, are they being given access to safe, legal totally un-coerced abortions if they want them"? participant, e-consultation, January 2011

The section of the Strategic Framework on essential services to support the prevention of unintended pregnancies could be strengthened by emphasising three issues. Firstly, while consultation participants felt that in many countries services existed, they stated that the services did not constitute an 'integrated package'. Instead, they were offered as stand-alone services. Failing to address the sexual and reproductive health and rights of women living with HIV in a comprehensive manner has led to the violation of their rights, including, for example, the documented forced sterilization of women living with HIV in four provinces of Indonesia (as reported by an e-consultation participant, December 2010).

Secondly, this section needs to emphasise the lack of quality counseling for women living with HIV when they do not want to get pregnant. Out of 591 respondents who completed the e-survey, 41% rated the overall quality of counselling that HIV-positive women receive

as average. A significant number (19%) rated the quality of counselling as poor and 9% as very poor.

Focus group discussions held in Jamaica highlighted that women in general do not receive counselling on sexual and reproductive health issues. The final report on the focus group discussions states that the participants agreed '[c]ounselling to promote safe pregnancies among PLHIV is limited or non-existent," and that, "[g]enerally, counselling is not done and indications are that an increasing number of women are having unplanned pregnancies." Some women do receive condoms but their own sexuality and contraceptive options are not routinely discussed. Additionally, women are routinely dissuaded from even the consideration of children and some are forced to be sterilised. Indications are that the lack of counselling around SRH has resulted in a high number of unintended pregnancies – women do not have the skills or information to plan pregnancies that would put their partners at least risk of infection and co-infection.

Counseling on unintended pregnancies should always support women and couples in making informed decisions about their reproductive health. This should include information about the option to have healthy babies. Participants of the consultative process stated that the goal should not be to prevent as many pregnancies as possible among women living with HIV. Service providers need to be aware of such perceptions. Programmes consistently have been perceived as putting the mother's health and rights at a lower value than those of the child. The Strategic Framework should support a shift, both in messaging and in the way providers see the value of the women as individuals and not just as mothers.

Evidence-based tools, such as case studies describing the realities of women facing unintended pregnancies and strategies for providing information and counseling to women living with HIV about their right to choose when and whether to have a child, would enable service providers to support women living with HIV.

Thirdly, this section should emphasise pre-conception care and awareness among women (especially young women), their partners and health providers. In the e-survey, out of 581 respondents, 58% felt that HIV-positive women and couples do not have enough support to conceive safely. The majority of respondents mentioned health workers' judgmental attitudes as the major problem affecting safe conception.

Components of the Service Package for Unintended Pregnancies:

In addition to integrating the three recommendations above, the following target populations are missing under the description of the components: men living with HIV, partners of women living with HIV (including HIV-negative men), couples and key populations (including women who are sex workers or who use drugs).

3.10 Goals and Targets

The goals and targets should reinforce ICW Global and GNP+ recommendations.

3.11 Strategic Framework Development Background

Finally, the process section of the final Strategic Framework should include the November 2010 consultation on the Prevention of Mother to Child Transmission where participants agreed on the importance of addressing all four components of PMTCT and further agreed that taking work forward on PMTCT will require broad partnerships, including communities living with and affected by HIV.

The consultations led by GNP+ and ICW Global to solicit the experiences and views of people living with HIV also need to feature in this section.

3.12 References and Tools

The categories are confusing to users. One suggestion is to place all documents in alphabetical order by author or to do so under the separate headings for 'policy', 'systems' and 'service delivery' in order to align them with the Strategic Framework's recommendations.

3.13 Supporting Policy and Programming Guidance

This section needs an explicit title that makes it clear that the supporting policy and programming guidance are for comprehensive PMTCT services. These sources should also be filtered by intended audience, or purpose, to ensure that the intended audience knows how to use these supporting documents.

5. Responsible use of language

*"I can easily see many who are against the whole idea of us as positive women even having sex, let alone children, thinking that it is 'positive women' who need to be eliminated... I think this is a very slippery slope and I am worried about the use of such emotive language in such a highly complex context. We are *not* just talking here about a "simple" vaccine to eliminate smallpox - we are talking about highly complex gender inequities and power imbalances. … We don't talk about 'elimination' of Malaria, but instead we use the term Roll Back Malaria, which is far more realistic"*. **– participant, e-consultation (December 2011).**

"Mother to child is just like from the child is in the womb until when the child comes out. So when you say 'parent' now, you know it's a long thing for both parents to help grow that child right through." **Female respondent (FGDs, Jamaica, January 2011)**

The language of 'elimination' should not feature anywhere in this document (for example, on page 4, paragraphs 1 and 4). The findings of the consultative process clearly show that 'elimination' of mother to child transmission is a difficult term among people living with HIV because it fails to recognise that HIV is not just a virus but is part of people's lives, affecting how the community relates to them on every level. The term 'elimination' can evoke fear and be disempowering for people living with HIV. It may prevent people from accessing necessary services and, subsequently, from being able to prevent passing on HIV to their child, if associated with that term. Use of the term 'elimination' in mother-to-child transmission should be revisited to clarify its meaning especially among people living with HIV. As revealed by the consultative process some understood 'eliminate' to mean eliminating positive women in order to eliminate mother-to-child transmission.

Similarly, there is need to revisit the term 'mother to child transmission' and agree on a term (s) that accurately describes HIV transmission to the child not only in biological terms, but without putting blame on the mother. The consultative process showed that the term 'mother to child transmission' is also perceived as problematic by many people living with HIV because it classifies the prevention measures in terms of the mother and the child and excludes the male partner. This is a barrier to male involvement. Women often internalize the negative message that they are to blame for their own status and for putting their child at risk. Providers should use neutral language so that women living with HIV do not carry home language that implies she is morally culpable in some way. In individual counseling sessions, therefore, the term 'mother to child' transmission should sufficiently be explained in order to avoid blaming the mother. Alternatively, terms such as 'parent to

child' transmission could be used instead. Indeed, although the global language may be very difficult to change, at the local level many counselors and advocates are already using the term 'parent to child' to avoid the negative implications of 'mother to child.'

All stakeholders must carefully consider choice of terminology in PMTCT programming to ensure definitions are clear, not normative, clouded in ambiguity or value loaded. People living with HIV must be consulted about terms used to describe goals and activities because these words affect how they feel about themselves and affect their ability to access services and to care for themselves, their partners and families.

6. Conclusion

The Strategic Framework is a welcome and necessary addition to the global PMTCT effort. The consultative process among PLHIV, which used a mixed method approach combining qualitative and quantitative feedback methods, revealed some areas in which the document should be revised based on the input of PLHIV consulted:

Services such as VCT should be taken to communities to encourage greater uptake. Provider-initiated testing should be implemented with community level and individual level information on the right to refuse the test and the right to have one's results kept confidential in addition to the benefits of consenting to the test and knowing one's status. Peer support should be recognized as a vital part of post test counseling and of PMTCT programming, both for men and women. Stakeholders must be held accountable for educating clinicians and other persons of authority on the rights of women and men living with HIV, their partners, and their children. Harmful attitudes among care providers is a significant barrier to successful PMTCT programs and must be addressed in every setting and at all levels of the global response.

In addition, sensitive use of language on sexual and reproductive health should make clear that the goal of comprehensive PMTCT is not to end all pregnancies among women living with HIV or to maximize the number of infants born HIV-negative at the expense of the mothers' rights. The document should be reviewed carefully to make sure that the language used does not imply that women living with HIV should feel that their life, health, or rights are less important than the sero-status of their unborn child.

People living with HIV have significant knowledge, experience and insight into issues affecting them, their families and their communities, and welcomed the opportunity to inform the development of the Strategic Framework. Meaningfully involving people living with HIV in the realization of the goals of PMTCT components 1 and 2 is vital. It ensures that policies and programmes are continually informed by a strong and relevant evidence base that is grounded in the reality of those hoping to benefit from them.

7. Appendix A: About the Project

About ICW Global and GNP+

The **International Community of Women Living with HIV and AIDS (ICW)** is the only global network run by and for HIV positive women. ICW seeks to raise awareness of the myriad abuses which members face across the global community. Currently membership covers over 120 countries around the world and members – all HIV positive women - come from all walks of life, include magistrates, solicitors and other members of the judiciary. www.icwglobal.org

The **Global Network of People Living with HIV (GNP+)** advocates to improve the quality of life of people living with HIV. As a network of networks, GNP+ is driven by the needs of people living with HIV worldwide. Based on emancipation and self-determination, GNP+ works with independent and autonomous regional and national networks of people living with HIV in all continents. www.gnpplus.net

Project Implementation Team

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8. Appendix B: Underlying Reports