Appendix B(4): Expert teleconference

Expert Teleconference on PMTCT Components One and Two:

Primary Prevention of HIV and Prevention of Unintended Pregnancies

Global Network of People Living with HIV

&

International Community of Women Living with HIV

24 January 2011

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Introduction

Across the world there are programmes and services that seek to prevent the transmission of HIV from a mother to a child. A five year strategic framework is being created by the Interagency Task Team (IATT) for *Prevention of HIV Infection in Pregnant Women, Mothers, and their Children* to help inform the way these important services should be organised and run.

The policy framework focuses specifically on the first two components of PMTCT:

1. Prevention of HIV among women of childbearing age
2. Prevention of unintended pregnancy among women living with HIV

Early December 2010, ICW Global and GNP+ began a collaborative consultative process among people living with HIV on the current draft of the Framework. Our goal has been to facilitate the meaningful involvement of those living with and affected by HIV into the final version of the document and to ultimately strengthen the document through our community's unique perspectives and insights into this area of HIV prevention. This process has included a moderated online consultation among individuals living with HIV, three facilitated focus groups among men and women living with HIV and their partners, and an extensive e-survey for those living with and affected by HIV. On January 24, 2010, ICW Global and GNP+ facilitated a conference call among experts in the prevention of mother to child transmission of HIV (PMTCT) field to discuss the framework. These experts included individuals living with HIV, service providers, advocates, academics, and our partners within the UN system.

Discussion

Overall, the group agreed that the first two components of PMTCT have received minimal attention in global PMTCT efforts and 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 scaling up these abuses as well.

Gender Based Violence

- The Framework should strengthen its references to gender-based violence as a barrier to women who would access HIV or reproductive health services.
- The Framework should emphasize the need for service providers to be educated on the risk of domestic violence following disclosure of one's status to a partner.

Voluntary Testing and Counseling

- 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. This was particularly important as community-based VCT was much preferred by young people and so reached more young men and women who are not yet having children but are close to or beginning their reproductive years. Learning that one is HIV-positive during pregnancy is particularly traumatic for women, and their partners. Enabling young women to learn their status before they access antenatal care will allow them to access those services that will benefit themselves and their partners that much earlier and also allow them to make informed decisions about whether and when to have children.
- Preconception care – worldwide, many women learn their HIV status during their antenatal care visit and so have missed the opportunity for preconception care. Information about preconception care should be included in voluntary testing and counseling.

Provider Initiated Testing and Peer Support

- Provider-initiated testing – many women report feeling pressured or forced to take the test, or that the test was mandatory, during their antenatal care visit. If a country has routine, provider initiated testing with an opt out option, there must be effective dissemination of information so that women know their rights, including the right to refuse the test, as well as information about the benefits to knowing one's status during pregnancy. In order to achieve this, information must be provided at the community level in addition to the individual level.
- Case studies and strategies for providing information to women living with HIV about their right to choose and when and whether to have a child would enable service providers to support women living with HIV.
- 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. Positively UK trains women as peer mothers to provide support emotionally and also to provide practical support to access services. Women often cite how helpful peer support is. However, there is a gap in peer support for men. WOFAK's work with couples in PMTCT settings indicates that men could 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.

- Counseling on unintended pregnancies must always include counseling on intended pregnancies as well. The information should allow couples to make informed decisions about their reproductive health. The goal should not be to prevent as many pregnancies as possible among women living with HIV. Programmes consistently put the mother's health and rights at a lower value than those of the child. The 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.
- 'Elimination of mother to child transmission' is a difficult phrase among people living with HIV because it fails to recognise that HIV is not just a virus but is part of people's lives. The term 'elimination' can evoke fear and be disempowering for people living with HIV, including people who are not able to access necessary services or are unable to prevent passing on HIV to their child.

'Parent to Child' versus 'Mother to Child'

- In individual counseling sessions, the term 'mother to child' transmission should be avoided and terms such as 'parent to child' transmission used instead. Women often internalize the negative message that they are to blame for their own status and for putting their child at risk. Providers should also use neutral language so that women living with HIV do not carry home language that implies she is morally culpable in some way.
- The term 'mother to child transmission' is also problematic 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.

Primary Prevention

- Post-test counseling is important for women who test negative so that they understand their risk factors, in particular their heightened risk during pregnancy.

- Post-test clubs for women who are pregnant and have tested HIV-negative might allow additional support and information-sharing among women to understand their risk factors and how to involve their partners.

Male Involvement

- Men must be a target population for each of the five key strategies and the importance of male involvement should be more strongly emphasized within the Framework with examples.
    - The inclusion of Men's Unions is one example of male involvement in their own and their families' health while living with HIV.
    - There is often no space for men to be involved in their partners' or their children's health. Cultural norms, an inability to access care or support at the same facilities as families, and lack of male peers or mentors to guide men who are living with HIV, or whose partners are living with HIV, on how to involve themselves are all major barriers to increased participation. Although there is a current trend to integrate women's sexual and reproductive health services, maternal and child health, and HIV care, treatment, and support, the Framework should make the case for the integration of men's reproductive and sexual health and HIV care, treatment, and support services within the same setting. Thus, the final integration yields family-centered care facilities where mothers, fathers, and their children are able to access the services they need. It is very difficult to encourage male involvement when they cannot access any services at the places their partners and children access them.
    - The Framework should address the gap in reproductive health services and information available to men living with HIV as well as men who are in sero-discordant relationships with women living with HIV.
    - The framework should include suggestions on how to provide information on voluntary testing and counseling and reproductive health for men and their partners in strategic places, for instance wherever condoms are offered.
- 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. Men need information so they can support their partners who are living with HIV to have healthy pregnancies and children. Many couples have reported waiting until past the first trimester to access antenatal care to avoid pressure to terminate the pregnancy. Couples also pretend pregnancies are accidents because of the incredible stigma associated with choosing to have children while living with HIV. This means that men who are in

serodiscordant relationships with women who are living with HIV are not able to access information on how to have children with their partner while controlling their risk of infection.

Healthcare Systems

- Greater emphasis should be placed on the role of community health providers, including traditional birth attendants. 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 greater 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. In addition, 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. As such the Framework's emphasis on nonjudgmental attitudes among service providers is vital from both a human rights perspective and a health outcomes perspective.

Conclusion

The Framework is a welcome and necessary addition to the global PMTCT effort. In addition to the practical case studies and strategies it highlights, it includes language on the sexual and reproductive health rights of women living with HIV. The language should be strengthened to 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. Women living with HIV should not be made to feel that their life, health, or rights are less important than the sero-status of their unborn child. Peer support should be recognized as a vital part of post test counseling and of PMTCT programming, both for men and women. 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. 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. Finally, the term 'mother to child transmission' implies that the mother is to blame for her child's infection and discourages male

involvement. While 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’. Similarly, the ‘elimination’ of ‘mother to child’ transmission fails to recognise that HIV is part of the lives of many people living with HIV. The framework should be clear that providers should seek to use neutral language in individual situations as one of many steps in reducing the fear and stigma associated with pregnancy for women living with HIV.