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A focus on women: a key strategy to preventing HIV among children

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Introduction

The *Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive* (Global Plan) is a road map that provides the foundation for country-led movements to ensure that children are born without (and remain free of) HIV and that their mothers are supported to remain healthy.[1] To this end, it sets two global targets: to reduce the number of new HIV infections among children by 90% and to reduce the number of AIDS-related maternal deaths by 50%.

It is critical that the actions taken to implement the Global Plan always reinforce and promote the human rights of women living with HIV and their infants. Women living with HIV should enjoy all human rights, including the right to life, health and non-discrimination; the right to found a family; and the right to information, confidentiality, expression, privacy, association, participation, an adequate standard of living and access to the benefits of scientific progress.

Access to HIV prevention, care, treatment and support services is integral to the enjoyment of the right to health and it is a prerequisite to exercising a wide range of other human rights. For infants, the enjoyment of the right to health requires benefitting from services that prevent transmission of HIV or, for children living with HIV, from infant-friendly paediatric ART (antiretroviral therapy) formulations.

The Global Plan recognizes that women living with HIV are central to an effective HIV response and calls for their meaningful engagement, including through active participation in mechanisms such as the Global Plan's Global Steering Group (GSG) and Inter-Agency Task Team. Women living with HIV—including those who already are mothers—should be supported and encouraged to engage at all stages of country and community programmes that are intended to prevent transmission of new HIV infections among children. Their experience means that women living with HIV are often well placed to be key partners in designing, implementing and independently monitoring policies and programmes. As a result, their voices should be heard and their knowledge and expertise should be recognized and upheld. In doing so, services will benefit by being truly grounded in the realities and needs of women living with HIV and their infants.

This issue brief is intended to inform and support partners in ensuring that the implementation of the Global Plan in their respective countries considers the best interests and rights of women. These partners include the relevant government ministries, health-care providers, policy-makers, development partners, donors and all NGOs that are involved in perinatal care. This brief is also intended for women living with HIV. It was prepared in consultation with women living with HIV, because they are central actors in the HIV response and should be engaged in a meaningful way in the implementation of the Global Plan.

The design of the paper also takes into account different perspectives about the use of language in discussions about HIV and health services for those living with HIV, as noted in the United Nations Population Fund's (UNFPA) *Preventing HIV and unintended pregnancies: Strategic framework 2011–2015*. For example, some people living with HIV have indicated that the term "elimination"—such as the elimination of mother-to-child transmission—can cause confusion and potential harmful effects when it is used on its own. Taken out of context like this, it can seem to connote an end to the lives of people living with HIV. This document makes clear that the term "elimination" should not be used alone, as short-hand or as a slogan. Stakeholders should carefully consider the terminology used in programming to ensure definitions are clear and not normative, clouded in ambiguity or value-laden.

What's the reality?

Of the estimated 35.3 million people living with HIV at the end of 2012, 50% (approximately 17.7 million) are women and almost half of all new adult HIV infections occur among women.[2] In 2012, of the estimated 1.5 million pregnant women living with HIV in low- and middle-income countries, 62% received effective antiretroviral drugs (ARVs) to prevent transmission of HIV to their children, up from 57% in 2011. In the 21 priority countries in sub-Saharan Africa identified in the Global Plan, the percentage of pregnant women living with HIV who are both eligible for antiretroviral therapy for their own health and who are receiving it increased from 25% in 2009 to 60% in 2012. While this constitutes a significant increase, 40% of pregnant women in need of antiretroviral treatment did not receive it in 2012 in these priority countries.[3] This contributes to the deaths of 37 000 women living with HIV in low- and middle-income countries who die from complications relating to HIV and pregnancy every year, whereas maternal deaths related to HIV in high-income countries are virtually zero.[4]

Women experience gender barriers when accessing services that include economic dependence and subjection to or fear of abandonment, abuse and violence. Even when women do access services, they report facing repeated stigma, discrimination,[5] and even physical violence that compromises their health and endangers their lives and those of their children.[6] This is problematic because discrimination within a health-care setting often results in the provision of care and delivery services to women living with HIV that is of poor quality, and in some instances, discrimination has led to involuntary sterilization or abortions.[7]

Similarly, disturbing trends in the increasing criminalization of HIV transmission can affect women (who often are the first member of a couple to test for HIV), discouraging pregnant women from accessing antenatal care for fear that they will test positive for HIV and be exposed to abuse and stigma, even from health-care professionals. Some laws criminalizing HIV transmission or exposure are drafted broadly enough to include transmission during pregnancy or breastfeeding and they can potentially undermine the effectiveness of child health, maternal health and perinatal HIV transmission programmes.

HUMAN RIGHTS CONCERNS IN THE CONTEXT OF ELIMINATING NEW HIV INFECTIONS AMONG CHILDREN INCLUDE THE FOLLOWING ISSUES:

- denial of prevention of mother-to-child transmission (PMTCT) services to pregnant women living with HIV;
- stigma, neglect and other negative attitudes and behaviours in health-care facilities directed at pregnant women living with HIV;
- lack of confidentiality for women living with HIV;
- lack of informed consent to testing and treatment, including insufficient information and counselling on a full range of issues and regimens in the context of sexual and reproductive health, as well as the procurement of "consent" under duress, which can include subjecting women living with HIV to sterilization or abortion without their informed consent;
- lack of sensitivity in PMTCT programmes towards the needs of women from marginalized groups or key populations at higher risk of HIV (e.g. poor women, young women, women with disabilities, sex workers and women who use or are dependent on drugs), including those who are living with HIV; and
- adopting or enforcing laws that allow for criminal prosecution for transmission of new HIV infections among children.

What can we achieve through the Global Plan?

The Global Plan resolves to work towards both ending new HIV infections among children and keeping their mothers alive by ensuring that:

- all women, especially pregnant women, have access to quality, life-saving HIV prevention and treatment services for themselves and their children;
- the rights of women living with HIV are respected and that women, their families and their communities are given the tools required to become empowered to engage fully in ensuring their own health and the health of their children;
- HIV, maternal health, new-born and child health and family planning programmes work together to deliver quality results that lead to improved health outcomes;
- communities, particularly women living with HIV, are enabled and provided with the tools to become empowered to support women and their families to access the HIV prevention, treatment and care that they need;
- adequate resources—both human and financial—are available from both national and international sources in a timely and predictable manner and success is acknowledged as a shared responsibility by governments and communities alike; and
- national and global leaders act in concert to support country-driven efforts and that these leaders are held accountable for delivering results.[8]

Programmes built around these issues should also address the urgent need to reduce HIV-related stigma and discrimination that women living with HIV face from within health services and their communities. This will not only help improve the quality of life among women and children living with HIV, but it will also lead to better health outcomes for all child-bearing women and their families.

What do women have to do with the "four prongs" or "components" of the Global Plan?

The Global Plan's implementation framework is based on a broad quadripartite strategy for eliminating new HIV infections among children and keeping mothers alive that is known as "the four prongs" (also referred to as "the four components"). These separate areas work together to provide a comprehensive approach towards not only ending new HIV infections among children, but also to keeping women and mothers alive and healthy. In the Global Plan, the four components are defined as follows.

- Component 1: Prevention of HIV among women of reproductive age within services related to reproductive health such as antenatal care, postpartum and postnatal care and other health and HIV service delivery points, including working with community structures.
- Component 2: Providing appropriate counselling and support and contraceptives, to women living with HIV to meet their unmet needs for family planning and spacing of births and to optimize health outcomes for these women and their children.
- Component 3: For pregnant women living with HIV, ensure HIV testing and counselling and access to the antiretroviral drugs needed to prevent HIV infection from being passed on to their babies during pregnancy, delivery and breastfeeding.
- Component 4: HIV care, treatment and support for women and children living with HIV and their families.[9]

To support the work around the Global Plan, there are many different ways that networks of women and mothers living with HIV connect with the health-care system.

- Some women living with HIV work inside health services, strengthening the ability of health workers to do their work and ensuring that pregnant women and mothers with HIV have an in-depth understanding of their realities. Acting as doctors, nurses and expert clients/mentors, women living with HIV counsel and support clients in order to generate not only greater adherence to the care that keeps women and their children healthy, but to ensure that they remain in care if they need it.[10]
- Women and mothers living with HIV also work outside of health services, acting as experts within community-based organizations that bring other women into contact with health care. They also act as proponents of health services that accommodate the needs and rights of women living with HIV. One example of this would be advocating for policies that deliver the appropriate services and correct medicines to women.[11]

Women at the centre of the four components of the elimination of new HIV infections among children and keeping mothers alive

Component 1: Prevention of HIV among women of reproductive age within services related to reproductive health such as antenatal care, postpartum and postnatal care and other health and HIV service delivery points, including working with community structures.

Ensuring that women of reproductive age remain HIV-negative is crucial to achieving the Global Plan. Efforts to prevent HIV amongst women should include the integration of HIV prevention services with sexual and reproductive health services. Integration efforts should address gender inequalities and gender-based violence, improve access to safe education for all girls and women and meet the needs of women throughout their lives, all while respecting their human rights.[12] The health-care system should be a safe and supportive place that helps women understand their options while enabling them to discuss their choices in an open manner with a health-care provider who can talk women through the situation in a respectful manner.[13]

Component 2: Providing appropriate counselling and support and contraceptives, to women living with HIV to meet their unmet needs for family planning and spacing of births and to optimize health outcomes for these women and their children.

An estimated 215 million women of reproductive age in developing countries would use family planning if they had access to it.[14] As a result of this widespread lack of services, the family planning needs and rights of women living with HIV, including women from key populations,[15] are still largely unmet.

National surveys indicate that the rates of unintended pregnancies among women living with HIV in some African countries range from 12% to 21%.[16] Without a greater effort to provide family planning, MDGs 3, 4, 5 and 6 will not be achieved.[17] That is why the sexual and reproductive health and rights of women should be key factors influencing country-level responses to HIV. Investment should be made in services that work for women because by providing family planning to women living with HIV and ensuring that mothers living with HIV can access effective care, treatment and support, the number of pregnancy-related deaths can be significantly reduced.[18] Furthermore, while integrating sexual and reproductive health and HIV services, efforts should be made to ensure that they are evidence-informed, non-judgemental, based on informed consent and confidentiality and accessible to women in all their diversity, including young women and women from key populations.

Regardless of their age, all women, including those from key populations, need access to information that is evidence-informed and easy to digest. This will give them the power to make decisions about family planning. When women are able to avoid unintended pregnancies, there are more resources to direct towards the nutrition, education and upbringing of each child. The spacing of pregnancies ensures that women and their children are stronger and healthier. Furthermore, contraception allows women to delay (or prevent) pregnancy and to avoid unsafe abortion or repetition of obstructed labour.[19] The wider family and community can also benefit from contraception.[20] The engagement of men and boys in gender-transformative community-based processes, for instance, will reduce violence against women and enable men to see that family planning that allows choices about whether and/or when to have children is a beneficial situation for everyone.[21]

Services should offer all women comprehensive information regarding their health care and treatment regimens. Women need safe and enabling environments that provide increased access to available contraceptive methods and more family planning options so that informed choices can be made and the best available health care pursued. The sexual and reproductive rights of women and mothers living with HIV should consistently be protected, promoted and upheld.

Component 3: For pregnant women living with HIV, ensure HIV testing and counselling and access to the antiretroviral drugs needed to prevent HIV infection from being passed on to their babies during pregnancy, delivery and breastfeeding.

When women are counselled and tested for HIV when they access health care to confirm a pregnancy, they are often the first person in a relationship to be diagnosed with HIV.[22] While helping women know their status is important, HIV testing should always be voluntary, confidential and non-coercive; mandatory HIV testing in antenatal care or any other setting is a violation of the rights of women and such practices hinder the ability of women to prevent perinatal transmission.[23] Provision of prenatal prevention education and confidential testing opportunities are important policies to protect women who wish to be tested, but who are afraid of their partner finding out without proper information and counselling.[24] Failure to uphold these rights has been found to deter women from accessing antenatal services because they fear judgemental health-care providers and the consequences of an HIV-positive diagnosis in their homes (including stigma or violence) once they disclose their status.[25]

Access to services and treatment for pregnant women living with HIV is paramount, but the provision of ARV medication should address more than just the health of the child. While access to treatment is improving for women, it is of concern that approximately half of the mothers eligible for treatment do not receive it. HIV also continues to be the leading cause of death of women of reproductive age.[26] Even where treatment is available, women with HIV often feel blamed for transmitting the virus to their child and they are subject to stigma, even in health-care settings. If women feel respected, supported and safe in health-care settings, they will use them again. As a result, ensuring that health services are respectful of the rights of women and user-friendly for women living with HIV is essential to reversing the “cascade effect” (where women are lost to follow-up services).[27] It is vital to ensure that women are safe and well (both throughout the pregnancy and beyond), that they are able to start antiretroviral therapy to protect their health,[28] reduce the risk of transmission to their babies and that their children are born (and remain) HIV-free.

Accessing health services is the human right of every woman living with HIV. Basic principles, such as informed consent and confidentiality, should always be upheld, especially with regard to HIV testing and treatment (both of which should include information and counselling). An HIV diagnosis is a shocking, life-changing event for most women; experiencing this during pregnancy is especially challenging.[29] Pregnancy also is a time of heightened vulnerability to gender-based violence for many women.[30] Therefore, it is essential to support and empower women who learn they have HIV during pregnancy so that they can make informed decisions about their own treatment and care, ultimately helping them to be in control of their own health. This can be done by providing unbiased information on available treatment regimens and helping women plan for not only their own health, but also for the delivery and safety of their baby.

APPROACHES TO THE PROVISION OF ARVS TO PREVENT TRANSMISSION OF NEW HIV INFECTIONS AMONG CHILDREN: A FOCUS ON LIFELONG TREATMENT FOR PREGNANT WOMEN

There are a number of approaches regarding the provision of ARV for the prevention of vertical transmission. Women have a right to choose from among these approaches, as the decision to initiate treatment should always be based on informed consent.

Currently there are three approaches to the provision of ARVs.

Since the Global Plan was launched, there has been growing debate about the benefits and effectiveness of these different approaches. Lifelong treatment consists of offering pregnant women antiretrovirals from the time of HIV diagnosis, regardless of their CD4+ count; this continues throughout pregnancy, childbirth and breastfeeding, with the women receiving ART for the rest of their lives. Lifelong treatment has been found to reduce transmission rates in future births, reduce potential transmission to future partners, simplify treatment and improve the woman's odds of survival.[31] While these outcomes are desirable, women living with HIV have expressed considerable concern that, starting treatment, especially for life, is a major decision and should be a personal choice based on informed consent. As some women living with HIV have pointed out, starting treatment for life has significant implications, even if taking antiretrovirals can provide potential benefits to people living with HIV and prevent the transmission of HIV to their loved ones ("treatment as prevention").[32]

Although access to treatment is a both a human right for the individual and an integral part of a public health approach, within the context of health-care delivery, the needs and concerns of the individual receiving treatment should always be put first. For instance, although studies now suggest that ARVs may cause more pre-term births, stillbirths and congenital abnormalities,[33] these risks are very much smaller than the risk of HIV infection for the unborn baby if the mother does not take ARVs. Individual pregnant women living with HIV should be provided full information on the risks and benefits such as these so that they are able to choose between the various treatment regimens based on informed consent.

There is also a need for women living with HIV to have greater participation and involvement in the delivery of these services. For instance, mothers living with HIV can provide crucial services within their communities by acting as counsellors, mentor mothers, medical advisors, nurses and physicians.[34] Women have stated that having peers who are living with HIV as counsellors and outreach workers is an extremely helpful approach that makes them feel at ease, that their concerns are heard and understood and that any advice they are given comes from experience and is grounded in reality.[35] Mentoring programmes can be established in clinics, allowing mothers to learn from peers who have "walked in their shoes."[36] Community engagement also complements work done by health facilities by engaging community members as extension workers, linking community-based and faith-based organizations and forging an enabling environment for treatment, care and support.

Engaging communities, particularly women living with HIV, in independently funded monitoring and evaluation of services can further increase their quality and uptake. A collaborative process between communities, health workers and local authorities benefits programmes by increasing ownership and accountability of programmes, improving the quality of discussions during contact time with service providers and enhancing both job satisfaction for health professionals and health outcomes.[37]

Component 4: HIV care, treatment and support for women and children living with HIV and their families.

The rights to choose the number and spacing of children; to have comprehensive and accurate information on health, treatment and family planning; and to have confidentiality protected should be upheld consistently in the context of HIV or sexual and reproductive health. This includes enabling women to choose when/if to start ARV treatment and which treatment they wish to receive (if a choice of regimen is available). As noted above, a rights-based approach requires ensuring that women living with HIV have access to appropriate information that enables them to make their own decisions about what is best for them.[38]

The rights of women and children are inextricably linked. Supporting mothers benefits their children and vice versa.[39] Children who have a healthy parent have a better chance of living a long and healthy life themselves,[40] while women who feel supported and empowered have the best opportunity to care for their children. Furthermore, women tend to invest their resources in child well-being more than men,[41] so healthy and empowered mothers result not only in children that are healthier, more educated and happier, but also in families that are more stable.

Male engagement, or the lack thereof, also has been found to affect the ability of women to access health services. Including men (where appropriate) in health services and strengthening couples counselling and testing can provide a chance to address gender disparities that impede women's access to care; it also provides an opportunity to reduce risk of HIV transmission.[42] In light of this, some countries have made a concerted effort to involve men in all aspects of these services. While the engagement of men can indeed be beneficial, their involvement should never infringe on the rights and autonomy of women. At the same time, ensuring that men have support to access services would also ensure that women are less likely to contract HIV in the first place.[43] For instance, if men were better supported, it could increase the likelihood that they would consistently wear condoms during sex or support their partners to use female condoms. It also could encourage greater male engagement in community programmes to stop intimate partner violence, promote greater uptake of treatment among men (for both their own health and to minimize HIV transmission) and increase participation in voluntary medical male circumcision programmes.

The way forward

Fully supporting women living with HIV before, during and after their pregnancy protects their rights and makes sound economic, political and social sense.[44] There also is a long-term financial benefit to ensuring the welfare of women beyond the individual and social benefits outlined above, reducing transmission rates and future treatment costs. As a result, ensuring the health of women has a positive impact on the community, improves health outcomes for all and contributes critically to broader development goals.

SUGGESTED PROGRAMMES AND INITIATIVES THROUGH WHICH HUMAN RIGHTS CONCERNS IN THE CONTEXT OF THE ELIMINATION OF NEW HIV INFECTIONS AMONG CHILDREN MAY BE ADDRESSED

1. Train health-care workers on non-discrimination, confidentiality, informed consent and other human rights and ethical principles.

2. Ensure that women living with HIV have full and complete information and understanding of sexual and reproductive health options, that they know the risks and benefits of each and that they have the ability to choose freely among them.

3. Empower women living with HIV to know their rights and local laws through legal literacy, patient rights information and legal services programmes.

4. Engage women living with HIV, human rights groups and women's organizations in a meaningful way (including through technical and financial support) in the development and implementation of PMTCT programmes.

5. Involve community-based organizations, including networks of women living with HIV, in supporting patients and health-care workers in improving access, uptake, quality and effectiveness of PMTCT services.

6. Monitor and evaluate human rights issues within PMTCT programmes to ensure that they are documented and addressed, including though community charters.

7. Reform laws, policies and practices that negatively impact human rights in the context of eliminating new HIV infections among children and keeping their mothers alive.

Key messages

1. Women living with HIV should be respected and valued partners in the response to HIV, including each step of the implementation of the Global Plan. Women living with HIV are powerful experts who are already working towards the goals of the Global Plan as leaders, doctors, nurses, community workers, volunteers, mentor mothers, friends and counsellors. More commitment and investment is needed to engage and involve women living with HIV as part of formal health care so that we can learn from their experiences.

2. Protect, promote and uphold the sexual and reproductive rights of all women living with HIV, including ensuring access to a wide range of contraceptive methods. Women's rights and children's rights should be recognized as inextricably linked. Supportive community engagement, including support from male partners, can indeed be beneficial, but it should never infringe on the rights and autonomy of women. Women must be equipped to exercise their rights and protect their own health, for their own lives and well-being. This, in turn, will also benefit their children and their communities.

3. HIV testing should always be accompanied by informed consent, confidentiality and counselling. Mandatory HIV testing in antenatal care or any other setting is a human rights violation.

4. Women living with HIV should always be given the opportunity to discuss their ARV treatment regimen and make their own decision about starting treatment. Women should not be coerced into treatment interventions and they should be fully informed of the benefits, risks and implications before any decision is made.

5. When integrating sexual and reproductive health and HIV services, efforts should be made to ensure that **services are evidence-informed, non-judgemental, affordable and accessible for women in all their diversity**, including young women and women from key populations.

6. There needs to be **continued investment in training health-care providers** to deliver services that are grounded in human rights and that focus on quality, non-discriminatory care that links sexual and reproductive health services and HIV care.

Endnotes

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