



**Maternal Health for Women Living with HIV**  
**Claim by International Community of Women Living With HIV (ICW)**  
**United Nations Commission on the Status of Women - 60<sup>th</sup> Session**

**To the Commission on the Status of Women**

Although the Millennium Development Goals (MDGs) undoubtedly increased global attention to maternal health and improvements in health facilities and medical treatments have cut maternal mortality rates by almost half in the past twenty years, maternal deaths caused by HIV have not seen similar reductions.<sup>1</sup> Globally, women living with HIV are 7 to 8 times more likely to die during pregnancy and the post-partum period than their HIV-negative peers.<sup>2</sup>

The International Community of Women Living with HIV (ICW) is the only global network for and by women living with HIV. ICW networks exist throughout the globe, and are inclusive of all self-identifying women living with HIV. ICW envisions a world where all women living with HIV live free of gender oppression, realizing and claiming our sexual, reproductive, legal, social, economic and health rights.

ICW has been the forefront of raising the voices of women living with HIV by supporting the meaningful involvement of women living with HIV to guide development and implementation of responsive policies and programming in HIV prevention, treatment, sexual reproductive health and maternal health with a specific focus on prevention of vertical, or mother-to-child, transmission (PMTCT) and reducing maternal deaths of mothers living with HIV. ICW recognizes and appreciates the impressive advancement of biomedical interventions that have enabled a reduction in the likelihood that a child will be born with HIV. However, with the adoption of the Sustainable Development Goals (SDGs), the challenge of improving maternal health for women and girls living with HIV stands at a critical juncture.

As the global scale-up of PMTCT efforts continues, women living with HIV, in particular pregnant women and those seeking to become pregnant, are increasingly central to the global aim of eliminating mother-to-child transmission of HIV. PMTCT programs often prioritize the protection of babies and infants, and this focus has frequently marginalized the rights, needs, and perspectives of women living with HIV within policies or program

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<sup>1</sup> World Health Organization, Trends in Maternal Mortality: 1990 to 2013 Estimates by WHO, UNICEF, UNFPA, The World Bank and the United Nations Population Division (2014), available at: [http://apps.who.int/iris/bitstream/10665/112682/2/9789241507226\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/112682/2/9789241507226_eng.pdf?ua=1) (45% decrease in maternal mortality from 1990 to 2013). Coceka Mnyani, et al., *A 15-year review of maternal deaths in a background of changing HIV management guidelines*. 21st Conference on Retroviruses and Opportunistic Infections, Boston, abstract 67, 2014 (there has been no change in the proportion of maternal deaths caused by HIV since 2007).

<sup>2</sup> Clara Calvert and Carine Ronsmans, *The contribution of HIV to pregnancy-related mortality: a systematic review and meta-analysis* (June 27, 2013) AIDS (10),1637, available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3678884/pdf/aids-27-1631.pdf>

development and design and has led to human rights violations, primarily in health facilities and to stigma and discrimination within communities.

Women living with HIV around the world report human rights violations in maternal health care settings. Systemic and institutional failures and barriers negatively impact the ability of women living with HIV to both initiate and remain in both HIV and maternal health services. These barriers include logistical barriers such as distance to HIV clinics, waiting times at the health facilities, loss of test results or long waiting times for test results, especially in instances of infant testing, and cost of transportation, especially for women living in non-urban areas. Women living with HIV also experience barriers related to lack adequate information about key aspects of preventing vertical transmission, including initiation to treatment for prevention of vertical transmission (Option B+), safe births and deliveries including use of elective caesarian section births, mixed information on breastfeeding and infant feeding, and benefits of early infant diagnosis and infant prophylaxis.

### **Maternal Mortality among Women Living with HIV:**

Maternal deaths among women living in the developing world is extremely concerning and has received global attention through the Millennium Development Goals (MDGs). Yet, women living with HIV in particular fare worse during pregnancy than other women. Although improvements in health facilities and medical treatments have cut maternal mortality rates by almost half in the past twenty years, maternal deaths caused by HIV have not seen similar reductions.<sup>3</sup> Worryingly, maternal mortality rates during this period have in fact increased in eight high HIV-prevalence countries in sub-Saharan Africa.<sup>4</sup>

Although experts continue to learn about the various causes of maternal mortality attributable to HIV during pregnancy, we do understand that maternal deaths occur in large part due to delays in the decision to seek care, in arriving at care, and in receiving appropriate care. Women living with HIV frequently experience abuse and discrimination within the healthcare setting—including a lack of informed consent, maternal abuse at the hands of healthcare providers, forced and coerced sterilization and abortion, refusals to provide services, hostile attitudes towards women living with HIV who seek to have children, stigmatization, breaches of confidentiality, and involuntary and coerced testing for HIV. As a result, women living with HIV are often reluctant to seek care or experience delays, and poor treatment or denial of services because of stigma from health care workers—all of which overwhelmingly contribute to maternal morbidity and mortality.

As the global scale-up of the prevention of vertical or mother-to-child transmission of HIV (PMTCT) efforts continues, women living with HIV, in particular pregnant women and those seeking to become pregnant, are increasingly central to the global goal of “getting to zero” children born with HIV. PMTCT programmes prioritize the protection of babies and infants,

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<sup>3</sup> WHO, UNICEF. Accountability for maternal, newborn and child survival: The 2013 Update. Geneva: WHO; 2013.

<sup>4</sup> WHO, UNICEF. Accountability for maternal, newborn and child survival: The 2013 Update. Geneva: WHO; 2013.

and this focus has frequently marginalized the rights, needs, and perspectives of women living with HIV within programme development and design and has led to human rights violations.

Although interventions to prevent vertical (mother-to-child) transmission of HIV have resulted in lower rates of transmission of HIV to infants, expectant mothers with HIV often face intense stigma, marginalization, and abuse from health care providers. For example, pregnant women living with HIV have reported certain discriminatory practices by service providers, such as using extra gloves or bleach and asking women to not come close to them, touch things, and cover their mouths while talking.<sup>5</sup> This discrimination and fear leads many women to avoid going to hospitals and to access care.

Many of these HIV-related maternal deaths can be prevented through meaningful access to high-quality, respectful obstetric care, as well as access to antiretroviral medications and adequate nutrition.<sup>6</sup> Maternal health priorities must not only focus on the elimination of new HIV infections in children, but on keeping mothers alive.

### **A Rights-Based Approach to Maternal Mortality**

Access to maternal care services for women living with HIV is only half of the picture—we must work together to ensure that women living with HIV have access to services that comply with the right to health and are available, accessible, acceptability and of quality. Critically, human rights violations are prevalent within the provision of services, with many obstetric services and PMTCT programmes being implemented in such a way as to deprive women of any real options or autonomy in making decisions about their own treatment and wellbeing. Governments must remain accountable in their obligations to respect, protect, and fulfill a wide array of civil and political as well as economic and social rights, including the right to the highest attainable standard of health.

Programming to addressing stigma and discrimination in maternal health settings is critical for improving maternal health outcomes for women living with HIV. As the world embarks on implementing the rollout of the new SDGs, it is imperative to ensure any development plans, policies and programs are inclusive of the voices of women living with HIV and must capture their maternal health needs and priorities.

ICW calls on the Commission on the Status of Women to recognize the need to eradicate barriers for improving maternal health among women and girls living with HIV particularly

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<sup>5</sup> International Community of Women Living with HIV and Global Network of People Living with HIV: Quality of family planning services and integration in the prevention of vertical transmission context: Perspectives and experiences of women living with HIV and service providers in Cameroon, Nigeria, and Zambia, at 20, available at: <http://www.iamicw.org/resources/document-library/quality-of-family-planning-services-and-integration-in-the-prevention-of-vertical-transmission-conte>

<sup>6</sup> See, e.g. Eva Lathrop, Denise J. Jamieson, and Isabella Danel, HIV and maternal mortality, *International Journal of Gynecology & Obstetrics* (July 16, 2014), available at: <http://www.ijgo.org/article/S0020-7292%2814%2900359-2/pdf>; Nan Li, Emmanuel Matchi, Donna Spiegelman, et al, Maternal mortality among HIV-infected pregnant women in Tanzania (May 2014), *Acta Obstetrica et Gynecologica Scandinavica*, 93:5, 463-468.

stigma, discrimination, abuse and violation of women's rights in health facility settings.

To realize this goal, ICW puts the following recommendations to CSW and Governments as they develop country implementation plans for the Post-2015 agenda and embark upon achieving the SDGs:

### **Ensure human rights**

Stronger protocols and training for healthcare workers at all levels is critical to ensure protection of the rights of women living with HIV, such as the right to informed consent for all services, including for HIV testing of women and their infants, and birthing options. Ensure ongoing sensitization and training, including in-service training, for health workers to provide more accurate information and reduce stigma and discrimination in order to create more welcoming mother- and child-friendly services.

### **Provide better quality information and counselling**

Women and mothers living with HIV must be provided with accurate and comprehensive information on all aspects of preventing vertical transmission of HIV. This includes addressing confusing messages on breastfeeding and other feeding options. Provide guidance for the requirements of informed consent, ensure quality of information on current guidance on early initiation of ARV treatment and lifelong treatment for pregnant women, and recommended ARV prophylaxis and accurate dosing for infants.

### **Prioritize peer support for women and girls in health facility and community**

Countries should prioritize capacity building and funding for networks and groups of women living with HIV to enable them to continue to provide essential peer support within their communities. Governments must invest in community initiatives, particularly those led by women living with HIV, to address barriers such as stigma and discrimination and rights violations to improve maternal health outcomes.

### **Engage women living with HIV to in planning and programming**

Women living with HIV offer a rich resource of lived experience that can support development and implementation of policies and programs that are responsive to the needs of women and girls. Supporting women and girls to engage in decision-making platforms offer an opportunity for women and their communities to understand and own programs thereby ensure sustainability.

### **Increase research**

Increase research on drivers of positive maternal health outcomes for women living with HIV. In particular, increase research to identify causes of higher maternal mortality and to develop evidence-based responses to maternal health disparities for women living with HIV.