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Statement submitted by International Council of AIDS Service Organizations, a non-governmental organization in consultative status with the Economic and Social Council

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.

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Statement

On Millennium Development Goals 4, 5 and 6 to reduce child mortality, improve maternal health and combat HIV/AIDS

Across the world, Governments continue scaling up national programmes to prevent vertical transmission of HIV. However, systemic barriers that prevent women living with HIV from accessing reproductive and maternal health services or adhering to drug and feeding regimens still pose the biggest threat to efforts to end vertical transmission and may lead them to drop out of prevention programmes. The prevention of transmission of HIV during pregnancy, delivery and/or breastfeeding has been a critical issue in the AIDS response globally and has become a cornerstone of HIV-prevention programming across the world. National AIDS programmes see prevention of mother-to-child transmission, as it is also known, as an important element in strengthening antenatal care as part of primary health-care services, and offer voluntary counselling and testing for women at antenatal clinics as central components of their AIDS responses.

Over the last decade, numerous declarations and guidelines have been developed and agreed upon, providing guidance to, and eliciting commitments from, Governments on, among other things, an intensified effort to end HIV by eliminating new HIV infections among children by 2015 and substantially reducing AIDS-related maternal deaths.

The International Council of AIDS Service Organizations would like to underscore, however, that despite the promises and commitments, women living with HIV are still not consistently at the centre of developing programmes for prevention of vertical transmission and maternal health. As a result, policymaking and programming at the national level are often carried out without understanding the realities of women’s lives, resulting in faulty planning that does not meet the requirements of those most in need of services. Along with gender inequity and violence, HIV-related stigma and discrimination remain significant deterrents for women needing to access and adhere to services. A recent study by the International Council of AIDS Service Organizations confirmed that pervasive stigma and discrimination in community and family settings and within health-care settings reduced uptake of prevention of vertical transmission programmes.

Greater visibility of women in public discourse, policy and practice has not fundamentally changed how women living with HIV are viewed: women are still blamed for bringing HIV into the relationship and the home. This spills over into the community and society, and impacts on how women living with HIV are treated in many different settings. Stigma and discrimination are experienced by people living with HIV at many levels across the prevention-treatment-care continuum and can result in reduced access to appropriate interventions. Women’s own fears of stigma and discrimination also impact their health-seeking behaviours. Women live with the fear of being stigmatized by the family, the community, or in health-care settings, and this results in women being unable to look after their sexual and reproductive health, for example, not going to health-service providers or not taking medication.

The women interviewed in the International Council of AIDS Service Organizations study highlighted the stigma-related challenges to the prevention of vertical transmission of HIV described below.

The women interviewed reported being blamed for “bringing the virus home”, either because they were the first to test for HIV or because they had a lower CD4 count; that led to violence, rejection and/or abandonment by their husbands or partners. Characteristically, the home is the place in which most women experience oppression and inequality. HIV-related stigma further contributes to the discrimination faced by women owing to their unequal status in society. Women often reported that their partners do not always accept their own HIV status and keep it hidden from them, adding to their feelings of betrayal.

Health-care settings can be anything but places of care. The women reported many and varied incidents of verbal abuse and discrimination which, apart from the trauma and emotional impact, also impacted on their health-seeking behaviour later. Incidents ranged from breaches of confidentiality and disclosure of their HIV status to denial of treatment. Many of the women reported receiving differential treatment from health-care workers, for example, nurses wearing extra pairs of gloves, or being made to wait the longest. Some were denied treatment or forced to go to other hospitals. One woman resorted to paying bribes in order to be treated.

Coercion on the part of health-care workers has been widely reported in many studies; the most blatant form is the forced sterilization of women living with HIV. In our study women also reported feeling coerced by health-care workers or doctors to follow their recommendation on a range of issues, including the method of contraception or delivery, the best infant-feeding option and, most importantly, the decision whether to have a child. While many women may have given in to the pressure, some women who were interviewed stood by their choices even against the advice of medical professionals.

In some cases, the experiences described by the women interviewed demonstrate the extremes that stigma and discrimination can lead to. The most inhumane treatment meets the definition of torture, contained in the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (art. 1), as

> any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as … punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.

The stories of these women clearly illustrate the most savage of actions executed with only one thing in mind: to inflict as much pain as possible as punishment for their HIV status.

In a rush to scale up prevention of mother-to-child transmission services to meet global targets, greater attention needs to be paid to how these services are implemented, in particular, to promote and protect the human rights of all women to full autonomy and non-discrimination. We recommend the following:

National laws, policies and programmes should:

- Ensure the meaningful involvement of women and mothers living with HIV in developing, implementing and evaluating all aspects of prevention of mother-to- child transmission policies, plans and programmes
- Ensure that national policies and programmatic guidance are reviewed/revised as necessary to address the stigma and discrimination reported by women living with HIV
- Enact laws and policies prohibiting discrimination on the basis of HIV status and establish mechanisms for reporting and remedying HIV-related discrimination that protect individuals from potential retaliation
- Ensure that adequate and relevant technical assistance is available to support the scale-up of rights-based prevention of mother-to-child transmission programmes and related health services
- Ensure that national policies, plans and programmes for the prevention of mother-to-child transmission are consistent with human rights principles and ethical requirements outlined in the World Health Organization (WHO) provider-initiated testing and counselling guidelines, the Guidelines on HIV and infant feeding, and the Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, including ensuring a supportive social, policy and legal framework for pregnant and breastfeeding women

Health-care settings should:

- Ensure that they are free of stigma and discrimination by incorporating human rights promotion and the ethical delivery of prevention of mother-to-child transmission services in health-care worker training, including coercion-free HIV testing and counselling, informed consent, confidentiality and privacy
- Regularly train health-care workers on the WHO Guidelines on HIV and infant feeding, with a focus on clear, current and accurate messages to pregnant and breastfeeding mothers living with HIV
- Ensure that sexual and reproductive health services and related maternal and child health services are integrated in prevention of mother-to-child transmission programmes in order to provide comprehensive care for women living with HIV
- Develop and implement strategies to engage male partners in prevention of mother-to-child transmission programmes in order to reduce stigma in the family
- Review national plans and budgets for preventing vertical transmission and ensure a stronger focus on sexual and reproductive rights of women living with HIV

Community and family settings should:

- Support community mobilization and collective advocacy to ensure that initiatives to reduce stigma, discrimination and violence against women living with HIV are central to the ambition and plans to meet the 2015 targets

- Develop and evaluate community-based interventions and programmes aimed at reducing stigma and discrimination faced by women living with HIV in the community and family settings
- Ensure that that pregnant and breastfeeding women living with HIV have access to community-based organizations and other community resources and tools

Rights-based normative guidance should:

- Ensure that WHO, the United Nations Children's Fund and the Joint United Nations Programme on HIV/AIDS incorporate the promotion and protection of human rights and the ethical delivery of services for the prevention of mother-to-child transmission and related maternal, newborn and child health services are integral elements of all future clinical, programmatic and operational guidance on the public health approach

In all settings, we see stigma made worse by gender prejudices and the idea that a woman's biology sets her destiny. We will never end AIDS unless we deal with the gender dimensions of HIV-related fear and ill-treatment.