



International Community of Women Living with HIV Submission to the UN Working Group on the Issue of Discrimination against Women in Law and in Practice

The International Community of Women Living with HIV (ICW) respectfully submits to the UN Working Group on the Issue of Discrimination against Women in Law and in Practice this report highlighting the discrimination and abuse experienced by women living with HIV in healthcare settings and good practices to address these human rights violations.

Women living with HIV frequently experience abuse and discrimination within healthcare setting, including a lack of informed consent, stigma, discrimination and physical 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, misinformation or denial of services because of stigma from healthcare workers—all of which serve as barriers to women living with HIV achieving their highest attainable standard of health and overwhelmingly contribute to adverse health outcomes such as maternal morbidity and mortality.

Key best practices for addressing these violations include supporting networks of women living with HIV to document and address rights violations, take serious steps to hold health care providers accountable and to address stigma, discrimination and abuse in healthcare settings, and finally increasing access to justice for women living with HIV who have experienced these violations.

Respectful Maternal Care

For women living with HIV, these experiences of stigma, discrimination, and abuse often occur in the context of seeking maternal health care. Experts have described seven major categories of disrespect and abuse that women encounter during maternity care, including physical abuse, non-consented clinical care, non-confidential care, non-dignified care (including verbal abuse), discrimination based on specific patient attributes, abandonment or denial of care, and detention in facilities.¹ Women living with HIV have reported experiencing these abuses, often exacerbated by stigma and discrimination based on their HIV status.

During contractions, the staff neglected me to take care of the negative patients first.

– Woman living with HIV, Cameroon²

At the ward, people living with HIV are kept at the extreme end of the room. They don't tell [the] other patients why, but we know we are kept there because of our status.

– Woman living with HIV, Nigeria³

¹ The White Ribbon Alliance, *Respectful Maternal Care: The Universal Rights of Childbearing Women*, at 1, available at: http://whiteribbonalliance.org/wp-content/uploads/2013/10/Final_RMC_Charter.pdf.

² Global Network of People Living with HIV and the International Community of Women 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.gnpplus.net/new-report-calls-dignity-rights-family-planning-programmes-women-living-hiv-cameroon-nigeria-zambia/>. (ICW/ GNP+ Family Planning Report)

Globally, women living with HIV are 7 to 8 times more likely to die during pregnancy and the postpartum period than their HIV-negative peers.⁴ 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. In countries with high maternal mortality, evidence suggests that “the fear of disrespect and abuse that women often encounter in facility-based maternity care is a more powerful deterrent to use of skilled care than commonly recognized barriers such as cost or distance.”⁵

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. However, PMTCT programmes prioritize the protection of babies and infants, 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.⁶

Option B+ (lifelong antiretroviral therapy) I started a long time ago because the doctors say “Listen we are not giving you these ARVs to save you, we are saving the baby, we don’t mind about your CD4 count.

– Woman living with HIV, Uganda⁷

Although interventions to prevent vertical 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.⁸ This discrimination and fear leads many women to avoid going to hospitals and to access care.

I know of a woman living with HIV who went to [an] antenatal [clinic and] at the point of delivery, [the doctor] went through the files and when he saw her file he said ‘This one, [I] am not touching her.’ She was on the stretcher already and [was] in labor. He said, “It’s a positive case... I didn’t leave my house to come and do a positive case today. I am not prepared.” The woman was left on the stretcher.

³ See *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*

⁴ Clara Calvert and Carine Ronsmans, *The contribution of HIV to pregnancy-related mortality: a systematic review and meta-analysis* (June 27, 2013) AIDS (10), at 1637, available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3678884/pdf/aids-27-1631.pdf>

⁵ The White Ribbon Alliance, *Respectful Maternal Care*, available at: <http://whiteribbonalliance.org/campaigns2/respectful-maternity-care/>.

⁶ See, e.g., Global Network of People Living with HIV, the International Community of Women Living with HIV, and the Coalition of Women living with HIV and AIDS, *Understanding the perspectives and/or experiences of women living with HIV regarding Option B+ in Uganda and Malawi*, available at: http://www.gnpplus.net/assets/wbb_file_updown/2793/Option-B+%20Understanding%20perspectives%20experiences%20of%20women%20living%20with%20HIV.pdf. In both Uganda and Malawi, women living with HIV saw Option B+ (lifelong antiretroviral therapy to all pregnant women living with HIV) presented as a programme primarily to protect the baby, with secondary benefits for the mother living with HIV.

⁷ See *Understanding the perspectives and/or experiences of women living with HIV regarding Option B+ in Uganda and Malawi*.

⁸ See *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*

– Woman living with HIV, Nigeria⁹

I had an HIV-positive pregnant friend and the nurse asked her to buy more gloves than necessary because she has to use double gloves for any contact with her not to be contaminated.

– Woman living with HIV, Cameroon¹⁰

Further, while accessing antenatal and maternal care, a recent qualitative study conducted by ICW & GNP+ indicates that women living with HIV may not receive full information about the realities and risks, such as higher morbidity, associated with Caesarean Section, as opposed to vaginal delivery and it is unclear from this data whether refusals of c-section was respected.¹¹

When I went to maternity to deliver that day... actually those people they see money. Personally, I was told; 'Prepare for caesarean.' Then I told them, who told you I cannot push? Who told you I cannot push?

– Woman living with HIV, Kenya (KEN2#5)¹²

The WHO recommendations state that “although Caesarean section has been shown to protect against HIV transmission, especially in the absence of ARV drugs or in the case of high viral load, WHO does not recommend it in resource limited settings specifically for HIV infection; rather it is recommended for obstetric and other medical indications.”¹³

The lack of information provided to women about the risks and benefits of c-sections reported in this study suggests a fundamental and pervasive violation of the rights of women living with HIV to informed consent and a need for better dissemination of updated guidance on the risks and benefits of c-sections for expectant mothers living with HIV.¹⁴

Forced and Coerced Sterilization: A Global Phenomenon

Forced and coerced sterilization is a particularly egregious example of the human rights violations in the healthcare setting. It occurs within a spectrum of violations that deny women living with HIV the autonomy to exercise their sexual and reproductive rights, including forced and coerced abortion and contraception, misinformation, lack of informed consent, stigma, discrimination, and abuse.

Voluntarily and freely chosen sterilization is an appropriate form of family planning for those women and men who do not wish to become pregnant or to have children. Sterilization that takes place

⁹ See *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*

¹⁰ See *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*

¹¹ Early Infant Diagnosis: Understanding the perceptions, values and preferences of women living with HIV in Kenya, Namibia Nigeria, at page 16 ICW and GNP+, 2015 available at <http://www.iamicw.org/resources/document-library/early-infant-diagnosis-report>

¹² See Early Infant Diagnosis: Understanding the perceptions, values and preferences of women living with HIV in Kenya, Namibia Nigeria,

¹³ Consolidated ARV guidelines, June 2013 Box 7.1: Special considerations for the care and management of pregnant women available at: http://www.who.int/hiv/pub/guidelines/arv2013/art/box7_1/en/

¹⁴ See Early Infant Diagnosis: Understanding the perceptions, values and preferences of women living with HIV in Kenya, Namibia Nigeria,

involuntarily, meaning without the full, free and informed consent of the woman herself is a violation of her human rights. Coerced sterilization, including, for example, sterilization that has been compelled in exchange for incentives such as loans or cash payments, access to nutritional supports such as formula or other services or supports or is a result of persuasion via unequal power dynamics, misinformation, exaggeration of the risks, abuse or discrimination, also constitutes a serious violation of fundamental human rights.

The forced and coerced sterilization of women living with HIV is a pervasive global phenomenon, and has been reported¹⁵ by women living with HIV along with other coercive practices in Bangladesh¹⁶, Brazil¹⁷, Cambodia¹⁸, Chile¹⁹, China²⁰, Democratic Republic of Congo²¹, Dominican Republic²², El Salvador²³, Fiji²⁴, Honduras²⁵, India²⁶, Indonesia²⁷, Kenya²⁸, Malawi, Mexico²⁹, Mozambique³⁰, Namibia³¹, Nepal³², Nicaragua³³, Pakistan³⁴, Philippines³⁵, South Africa³⁶, Sri Lanka³⁷, Swaziland³⁸, Tanzania³⁹, Thailand⁴⁰, Uganda⁴¹, Ukraine⁴², Venezuela⁴³, Viet Nam⁴⁴ and Zambia.⁴⁵

¹⁵ These experiences have either been formally recognized or are anecdotal reports from women living with HIV and their networks.

¹⁶ Positive and Pregnant: How Dare You. A study on access to reproductive and maternal health care for women living with HIV in Asia, 2010 WAP+ (ICW ASIA PACIFIC) Available at: <http://www.apnplus.org/main/share/publication/APN+%20Reproductive%20and%20Maternal%20Health%20Report%20A4%2013%20April.pdf>

¹⁷ Oliveira, F., Kerr, L., Frota, A., Nóbrega, A., Bruno, Z., Leitão, T., Kendall, C. and Galvão, M. (2007) 'HIV-positive women in northeast Brazil: Tubal sterilization, medical recommendation and reproductive rights', AIDS Care, 19:10, 1258 - 1265 Available at: <http://dx.doi.org/10.1080/09540120701405411>

¹⁸ See Positive and Pregnant: How Dare You.

¹⁹ FS v. Chile. Issue Summary available at <http://reproductiverights.org/en/press-room/chile-forced-sterilization-lilian-hiv-aids-oped>

²⁰ People Living with HIV Stigma Index Asia Pacific Regional Analysis 2011 available at http://www.aidsportal.org/atomicDocuments/AIDSPortalDocuments/20111108205818-PLHIVStigmaIndex_AsiaPacific2011.pdf

²¹ L.T.Satande, et al. From redress to rights: forced sterilization of women living with HIV in Sub-Saharan Africa. : AIDS 2010 – XVIII International AIDS Conference: Abstract no. CDD0956

²² Human Rights Watch A Test of Inequality: Discrimination against Women Living with HIV in the Dominican Republic 2004 available at <http://www.hrw.org/sites/default/files/reports/dr0704.pdf>

²³ Reproductive rights violations experienced by women with HIV in Mesoamerica, Tamil Kendall Phd. Research Presentation January 13, 2014 Research Conducted in Partnership with ICW Latina and Balance. Summary available at :

http://www.wilsoncenter.org/sites/default/files/Kendall_ReproRightsViolations_jan27.pdf

²⁴ See People Living with HIV Stigma Index Asia Pacific Regional Analysis, 2011

²⁵ See Kendall, Phd. Reproductive Rights Violations experienced by women with HIV in Mesoamerica.

²⁶ See Positive and Pregnant: How Dare You.

²⁷ *Id.*

²⁸ At Risk Rights Violations of HIV-Positive Women in Kenyan Health Facilities, Center for Reproductive Rights 2008 Available at: <http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/At%20Risk.pdf>; Kasiva F, Kiio G.; See also Robbed of Choice: Forced and coerced sterilization experiences of women living with HIV in Kenya. Nairobi, African Gender and Media Initiative, 2012.

²⁹ See Kendall, Phd. Reproductive Rights Violations experienced by women with HIV in Mesoamerica.

³⁰ ICW Southern Africa Regional Network Anecdotal Member Reports.

³¹ The Forced and Coerced Sterilization of HIV Positive Women in Namibia, March 2009 <http://www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf>

³² See Positive and Pregnant: How Dare You.

³³ See Kendall, Phd. Reproductive Rights Violations experienced by women with HIV in Mesoamerica.

³⁴ <http://reliefweb.int/sites/reliefweb.int/files/resources/protecting-rights-of-key-hiv-affected-wg-health-care-settings.pdf>

³⁵ See People Living with HIV Stigma Index Asia Pacific Regional Analysis 2011

³⁶ *Id.*

³⁷ Busting the myth that sterilization can end AIDS available at <http://www.ohchr.org/EN/NewsEvents/Pages/ForcedSterilization.aspx>

³⁸ ICW Southern Africa Member Reports; Member Network Swaziland Network for People Living with HIV/AIDS (SWANEPHA) Swaziland: HIV Stigma Still a Barrier available at <http://www.irinnews.org/report/96761/swaziland-hiv-stigma-still-a-barrier>

³⁹ International Community of Women Living with HIV/AIDS (ICW); HIV Positive Women in Thailand: Their Voices and Choices HIV Bencha Yoddumnern-Attig et al. eds., 2004, available at <http://www.hivpolicy.org/Library/HPP000687.pdf>

⁴⁰ See Busting the myth that sterilization can end AIDS

⁴¹ ICW East Africa Regional Network Anecdotal ICW Member Reports- Uganda.

⁴² Human Rights Watch (2006), Rhetoric and Risk: Human Rights Abuses Impeding Ukraine's Fight against HIV/AIDS. Available on-line at <http://www.hrw.org/en/reports/2006/03/01/rhetoric-and-risk>

⁴³ See Busting the myth that sterilization can end AIDS

⁴⁴ People Living with HIV Stigma Index Asia Pacific Regional Analysis 2011

⁴⁵ See <http://www.irinnews.org/report/90337/southern-africa-more-sterilizations-of-hiv-positive-women-uncovered>; See also L.T.Satande, et al. From redress to rights: forced sterilization of women living with HIV in Sub-Saharan Africa. : AIDS 2010 – XVIII International AIDS

Women from around the world have reported these violations, but despite differences of geography, the stories of women living with HIV who have experienced coercive or forced sterilization are disturbingly similar and are frequently reported in the context of prevention of vertical transmission. The United Nations High Commission on Human Rights and UNAIDS have also highlighted concerns about the use of forcible and coercive measures in the context of prevention of vertical transmission and in particular the counterproductive outcome of coercive measures in terms of meeting public health goals.⁴⁶

Women living with HIV report being sterilized during delivery via caesarean section for the purposes of prevention of vertical transmission of HIV to the baby or while undergoing other surgical procedures. They routinely report being asked to sign papers or verbally consent to sterilization while in labour, or health care workers obtaining consent for the procedure from their husbands or fathers. Women living with HIV frequently experience discriminatory practices such as refusal to provide services, hostile attitudes towards women who seek to have children, stigmatization at hospitals and medical centers by health care providers and staff and breaches of confidentiality. In some cases, women living with HIV report being offered nutrition or cash supports and services in exchange for undergoing sterilization. Women living with HIV report fear that they will be denied life-saving medicines or treatments if they do not undergo sterilization. Many women report that they do not even learn that they have been sterilized without their consent until they are trying to have another child.⁴⁷

During the cesarean and under the effects of the anesthesia they forced her into sterilization so that she couldn't have more children. She didn't sign a consent. When she was recovering from the anesthesia, she saw that her finger was stained with ink.

– Woman living with HIV, Mexico⁴⁸

I found out they had sterilised me when I had the abortion without my consent. I was angry and I didn't want to sign the form. The doctor who did the sterilisation brought me to a room. He said the operation was difficult and said it was up to me if I filled in the form or not, but if I did I would receive money from my administrative district to help with my nutrition during my recovery. In the end I signed and I got the money [USD23].

– Woman living with HIV, Viet Nam⁴⁹

They forced me to accept sterilization by telling me that if I didn't, they wouldn't help me with milk for my children.

– Woman living with HIV, El Salvador⁵⁰

Conference: Abstract no. CDD0956

⁴⁶ Office of the United Nations High Commissioner for Human Rights & Joint United Nations Programme on HIV/AIDS (UNAIDS), International Guidelines on HIV/AIDS and Human Rights 2006 Consolidated Version para. 96 (2006). available at <http://www.ohchr.org/Documents/Publications/HIVAIDSGuidelinesen.pdf>

⁴⁷ Positive and Pregnant: How Dare You. A study on access to reproductive and maternal health care for women living with HIV in Asia, 2010 WAP+ (ICW ASIA PACIFIC) Available at: <http://www.apnplus.org/main/share/publication/APN+%20Reproductive%20and%20Maternal%20Health%20Report%20A4%2013%20April.pdf>; Reproductive rights violations experienced by women with HIV in Mesoamerica, Tamil Kendall Phd. Research Presentation January 13, 2014 Research Conducted in Partnership with ICW Latina and Balance. Summary available at : http://www.wilsoncenter.org/sites/default/files/Kendall_ReproRightsViolations_jan27.pdf; “I feel like half a woman all the time”: A qualitative report of HIV positive womens experiences of coerced and forced sterilizations.” Mthembu, P., Essack, Z, Strode, A, Available at <http://africawln.org/wp-content/uploads/2012/06/HIV-Women-being-sterilized.pdf>

⁴⁸ Reproductive rights violations experienced by women with HIV in Mesoamerica, Tamil Kendall Phd. Research Presentation January 13, 2014 Research Conducted in Partnership with ICW Latina and Balance. Summary available at : http://www.wilsoncenter.org/sites/default/files/Kendall_ReproRightsViolations_jan27.pdf;

⁴⁹ See Positive and Pregnant: How Dare You.

⁵⁰ See Tamil Kendall, Phd.

The nurse told me if I did not agree to tubal ligation then Blue House will not take care of my maternity expenses. I got to Pumwani and I was given a form, the nurses insisted I had to sign. They called me 'a useless woman with HIV.' I took the form and signed it because I was kept waiting in the labor ward until I signed.

– Woman living with HIV, Kenya⁵¹

Good Practices & Recommendations:

1. Ensure human rights: Take steps to address stigma, discrimination, mistreatment, and abuse in healthcare settings.

- a. 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;
- b. Ensure that efforts to improve maternal health include mandatory training for all personnel who provide health care services on gender equality, autonomy, and human rights.
- c. Develop PMTCT programs and services that ensure women living with HIV are able to make voluntary, fully informed, autonomous decisions about whether and when to be treated.

2. Engage women living with HIV as peer supports and in the conceptualization, planning and implementation of 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.

- a. Meaningful involvement of women living with HIV in the design, implementation, and evaluation of programs and services.
- b. Peer support programs, that promote comprehensive, holistic care and safe pregnancies and deliveries and provides accurate and accessible information and psychosocial support to women living with HIV;
- c. Support networks of women living with HIV to educate other women about their rights to empower them in their exchanges with healthcare workers;
- d. Support networks of women living with HIV to document human rights abuses.

3. Increase access to justice for women living with HIV, including through the courts or alternative mechanisms to report rights violations and mistreatment:

In addition to justice through the courts and compensation for women living with HIV who have experienced sterilization:

- a. Holistic approach to the needs of women living with HIV who have experienced forced and coerced sterilization, provide medical examinations for women who believe that they may have been sterilized, offer medical reversals for those women whose situations permit

⁵¹ See Robbed of Choice.

- women living with HIV who have experienced forced or coerced sterilization and ensure that policy or regulatory prohibitions on adoption for people living with HIV are reformed;
- b. Develop and support alternative grievance mechanisms, in partnership with women living with HIV, where healthcare providers can be held accountable and where women living with HIV can report violations with out fear of consequences and with out the barriers posed by legal process.

Examples of Justice through the Courts:

- i. ICW's Network the Namibian Women's Health Network in Namibia first exposed the issue of forced and coerced sterilization and in 2010, as a result of ICW's advocacy and documentation efforts, Namibian women who had been forcibly sterilized brought suit against the Namibian Ministry of Health and Social Services. In November 2014, the Namibian Supreme Court upheld the lower court's decision that three HIV-positive women had been forcibly sterilized without proper consent during emergency caesarean deliveries. Although the three women were successful in their efforts, many more women have experienced forced and coerced sterilization and have little access to redress.
- ii. Our regional network in South Africa, ICW Southern Africa, has also been actively documenting these efforts and recently filed its first lawsuit in South Africa, which settled out of court. Media around the case caused over 40 more women to report forced or coerced sterilization in South Africa.
- iii. The sterilization of women living with HIV in Kenya women without their informed consent first sparked outrage in 2012, when a report published by the African Gender and Media Initiative (GEM), in partnership with local networks of women living with HIV titled 'Robbed of Choice' described the experiences of 40 women living with HIV who had been forcibly or coercively sterilized due to their HIV positive status. As a result of the documentation, the Kenya Legal and Ethical Issues Network on HIV & AIDS (KELIN) and GEM filed two lawsuits on behalf of five women living with HIV against healthcare providers, county health officials and the Health Cabinet Secretary for violations of their human rights.⁵² These cases are still pending.

4. Increase research

- a. 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 including stigma and discrimination.

⁵² The International Community of Women Living with HIV filed 2 applications on 29 July, 2015 in the High Court of Kenya seeking to be enjoined onto two cases filed by Mr. Allan Maleche on behalf of five women living with HIV who have been unconstitutionally sterilized by way of tubal ligation, the Kenya Legal and Ethical Issues Network on HIV & AIDS (KELIN) and the African Gender and Media Initiative (GEM). ICW has been successful in its bid to join Petition 606 of 2014 as the 1st Interested Party while their application to be enjoined in Petition 605 of 2014 will be heard on 2 November 2015.