REPUBLIC OF KENYA

IN THE HIGH COURT OF KENYA AT NAIROBI

CONSTITUTIONAL AND HUMAN RIGHTS DIVISION

PETITION NO. 606 OF 2014

IN THE MATTER OF THE ENFORCEMENT OF THE BILL OF RIGHTS UNDER ARTICLE 19, 20, 21 AND 23 OF THE CONSTITUTION OF KENYA (2010)

AND

IN THE MATTER OF THE ALLEGED CONTRAVENTION OF ARTICLES 26, 27, 28, 29, 31, 33, 35, 43, 45 AND 46 OF THE CONSTITUTION OF KENYA (2010)

BETWEEN

L.A.W..... 1ST PETITIONER

KENYA LEGAL AND ETHICAL ISSUES

NETWORK ON HIV & AIDS (KELIN)..... 2ND PETITIONER

AFFICAN GENDER AND MEDIA INITIATIVE

TRUST (GEM)..... 3RD PETITIONER

AND

MARURA MATERNITY & NURSING HOME..... 1ST RESPONDENT

COUNTY EXECUTIVE COMMITTEE MEMBER

IN CHARGE OF HEALTH SERVICES – NAIROBI

COUNTY .....2ND RESPONDENT

THE CABINET SECRETARY,

MINISTRY OF HEALTH .....3RD RESPONDENT

THE HON. ATTORNEY GENERAL.....4TH RESPONDENT

AND

THE SECRETARIATE OF THE JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS

(UNAIDS Secretariat) .....1st AMICUS CURIAE

PROFESSOR ALICIA ELY YAMIN.....2ND AMICUS CURIAE

NATIONAL GENDER AND EQUALITY

COMMISSION (NGEC).....3RD AMICUS CURIAE

THE INTERNATIONAL COMMUNITY OF WOMEN

LIVING WITH HIV (ICW).....INTERESTED PARTY

INTERESTED PARTY'S WRITTEN SUBMISSIONS

A. INTRODUCTION

1. The Constitutional Petition filed herein is about seeking justice for an indigent woman who has been subjected to an unlawful sterilization procedure because of her HIV status. the 1st Petitioner was subjected to sterilization via a medical procedure known as bilateral tubal ligation on the grounds that she is HIV positive. This procedure was undertaken without her knowledge or consent by staff at the Marura Maternity and Nursing Home, the 1st Respondent herein.

2. The procedure was undertaken without the 1st Petitioner's informed consent and thus in violation of her constitutional and human rights including; reproductive health rights; rights to have and found families; rights to privacy; rights to human dignity and equality; right to health; freedom of security of the person; right to non-discrimination and equality as submitted to in detail by the Petitioners Advocates herein.

B. THE PETITIONERS CASE

3. We submit that the Petitioners have ably discharged their respective legal burden of proof as per the evidence on record and as well submitted by their advocates on record. We therefore fully associate ourselves with the Petitioners submissions on record and wish not to reiterate the same herein.

4. Guided by the Interested Party's interest in the Petition herein as captured in its application to be joined to these proceedings, we will in the first instance, briefly submit on the 1st Petitioner's case as follows:

5. My Lord, we urge the court to keenly consider the weight of the 1st Petitioner's oral evidence as well as her depositions stated in her affidavit in support of the Petition sworn on 10th September 2015 and the attachments thereof including expert reports by the Obstetrician/gynaecologist Dr. Khisa Weston Wakasiaka, clinical psychologist Elizabeth A. Khaemba and Psychiatrist Dr. David E. Bukasi.

6. It is our humble submissions that the issue of informed consent lies at the core of the 1st Petitioners case and would thus wish to additionally submit

on the same. The term 'consent' has been defined in section 2 of the HIV and AIDS Prevention and Control Act No. 14 of 2006 which states thus;

"consent" means consent given without any force, fraud or threat and with full knowledge and understanding of the medical and social consequences of the matter to which the consent relates;".

7. Taking the above definition into consideration and reading it together with the International Federation of Gynecology and Obstetrics (FIGO) Guidelines on female sterilisation (2011)[1], it is our humble submission that in the context of tubal ligation as a form of contraceptive, this definition includes the following in its meaning: -

   i. That an explanation must be made in the language understood by the patient about the medical and social consequences relating to the decision in issue;

   ii. That full medical information on potential risks and benefits arising from the decision has been given to the patient;

   iii. An explanation that the decision is voluntary and that failure to consent would not result in any penalty or adverse consequences;

   iv. An explanation that the patient can accept or refuse to take the decision;

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1 https://www.womenenabled.org/pdfs/International_Federation_of_Gynecology_and_Obstetricts_Sterilization_Guidelines_FIGO_2011.pdf?attredirects=0

v. That the circumstances of making the decision must not be vulnerable circumstances that would vitiate sound judgement in relation to the matter is issue e.g seeking consent from a woman in labour pains or due to deliver;

vi. That it entails informed consent which is a burden beyond written consent.

8. Coerced sterilization, or sterilization that has been compelled in exchange for incentives such as loans or cash payments; or access to nutrition or other services or supports or a denial of these services or that is a result of persuasion via unequal power dynamics, misinformation, exaggeration of the risks of HIV transmission, or that occurs during labor or childbirth or as a result of abuse or discrimination or failure to give full information on an issue subject matter of informed consent, constitute recognized forms of unlawful consent and represent violations of human rights.[2]

9. Bearing the above in mind, we wish to point out to court that the pleadings and evidence on record has brought out, *interalia*, the following facts as relates to the 1st Petitioner;

i. She was subjected to tubal ligation without being provided with the full information and made to understand the medical and social consequences of tubal ligation.

[2]Against Her Will: The Forced and Coerced Sterilization of women worldwide., Open Society Foundations Available at: https://www.opensocietyfoundations.org/sites/default/files/against-her-will-20111003.pdf Last Accessed June 13, 2016.

ii. This position is captured in her uncontroverted evidence captured in her aforestated Supporting Affidavit at paragraph 21 where she depones thus:

"THAT I went back to the Community health worker who had given me the voucher earlier in 2006 and asked her what 'TL' actually meant and she explained to me that the voucher she gave me written TL meant that I was also going to undergo tubal ligation during caesarean section and that during the birth of my child at Marura Nursing Home the doctor conducted a bilateral tubal ligation on me".

10. The Medical evidence on record by Dr. Khisa Weston Wakasiaka confirms that the 1st petitioner underwent the tubal ligation procedure which is permanent method of contraception.

11. Your lordship, it is our humble submissions that the 1st Petitioners has ably demonstrated that she was subjected to the tubal ligation without her consent as envisaged in law thus amounting to forced and/or coerced tubal ligation which is unlawful. The petitioners have thus discharged the legal burden of proof as envisaged under section 107 of the Evidence Act, Cap 80 of the Laws of Kenya.

12. Whereas the 1st Respondent claimed that the 1st Petitioner signed a consent form, they did not avail any direct evidence that addressed the essence of explanation, full knowledge and understanding of tubal ligation procedure as a matter of meeting consent requirements and whether indeed the same was offered to the Petitioner. As a matter of fact, 1st Respondent's witness Sophia Wanjiku denied knowledge of preparation and administration of the

consent form exhibited in her affidavit on record during cross examination by the Petitioners Advocate.

13. Sophia also confirmed that the 1st Petitioner was surgically operated on by Dr. Wangwe who still consults for 1st Respondent hospital but yet again the 1st Respondent failed to avail the said doctor to adduce any evidence as to whether indeed the 1st Petitioner's informed consent was procured in the manner envisaged in law.

14. Obtaining informed consent prior to an invasive medical procedure is critical to ensure the fundamental rights of the patient are not violated. The UN Special Rapporteur on the right to everyone to the enjoyment of the highest attainable standard of physical and mental health (UN Special Rapporteur on Health) has affirmed the foundational import of informed consent stating that "guaranteeing informed consent is a fundamental feature of respecting an individual's autonomy.

15. The components of informed consent are well-established. The Kenya National Patients' Rights Charter (2013) states (at Chapter 1 Clause 8):
"Every person, patient or client, has a right(sic) to be given full and accurate information in a language one understands about the nature of one's illness, diagnostic procedures, proposed treatment, alternative and the costs involved for one to make a decision except in emergency cases. The decision shall be made willingly and free from duress."

16. In the Landmark case in South Africa, Castell V de Greeff 1994(1) SA 408 (C), Ackerman J outlined what constituted informed consent where he opined, (at 425):

"For consent to operate as a defence, the following requirements must, inter alia, be satisfied: the consenting party must have had knowledge and been aware of the nature of the harm or risk; the consenting party must have appreciated and understood the nature and extent of the harm and risk; the consenting party must have consented to the harm and assumed risk; the consent must be comprehensive, that it extend to the entire transaction, inclusive of its consequences.

17. In the United Kingdom, the Court in *Montgomery v Lankshire Health Board (2015) UKSC11,* affirmed this and further noted that patients must be presented with alternatives to the medical procedure discussed as part of the informed consent process.

"An adult person of sound mind is entitled to decide which, if any, of the available forms of treatment to undergo, and her consent must be obtained before treatment interfering with her bodily integrity is undertaken. The doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments."

18. The Court further noted that medical personnel must ensure that the information is presented in an understandable manner such that she has all the necessary information to make a decision:

"Secondly, the doctor's advisory role involves dialogue, the aim of which is to ensure that the patient understands the seriousness of her condition, and the anticipated benefits and risks of the proposed treatment and any reasonable alternatives, so that she is then in a position to make an

informed decision. ***This role will only be performed effectively if the information provided is comprehensible.*** ***The doctor's duty is not therefore fulfilled by bombarding the patient with technical information which she cannot reasonably be expected to grasp, let alone by routinely demanding her signature on a consent form."***

19. The 1st Respondent failed in its obligation to procure lawful informed consent from the 1st Petitioner. It instead resorted to testifying about general hospital procedures on obtaining consent which in any event did not meet the legal tenets of a consent as submitted herein above. The 2nd, 3rd and 4th Respondents did not also adduce any evidence at all either in response or in denial of the evidence put forth by the Petitioners that they had failed to discharge their obligation. We thus submit that the Respondents failed to discharge the evidential burden of proof upon the same being shifted to their shoulders.

20. We thus urge the court to rely of the findings of the majority decision of the Supreme Court in **Presidential Election Petition No. 1 of 2017** between **Raila Amolo Odinga & Another vs. IEBC & 2 Others (2017) eKLR** who had the following to say on the evidential burden of proof in **paragraphs 132** and 133 thereof: -

[132] Though the legal and evidential burden of establishing the facts and contentions which will support a party's case is static and "remains constant through a trial with the plaintiff, however, "depending on the effectiveness with which he or she discharges this, the evidential burden keeps shifting and its position at any time is determined by answering the question as to who would lose if no further evidence were introduced.

[133] It follows therefore that once the Court is satisfied that the petitioner has adduced sufficient evidence to warrant impugning an election, if not controverted, then the evidentiary burden shifts to the respondent, in most cases the electoral body, to adduce evidence rebutting that assertion and demonstrating that there was compliance with the law or, if the ground is one of irregularities, that they did not affect the results of the election. In other words, while the petitioner bears an evidentiary burden to adduce 'factual' evidence to prove his/her allegations of breach, then the burden shifts and it behooves the respondent to adduce evidence to prove compliance with the law…..

21. We wholly adopt the Petitioners submissions on violations of the 1st petitioner's rights arising from the 1st Respondents failure to act within the law as well as 2nd , 3rd and 4th Respondents failures as duty bearers and consequently urge the court to find in favor of the Petitioners and grant the orders sought herein.

22. Our further submissions my Lord is that the Interested Party's interest in this matter is informed by the lived reality that some of its members across the world who are HIV positive women have been subjected to sterilization without their informed consent on the basis of their HIV status while some are at continued risk of being victims such as has been raised in the petition herein.

23. The Interested Party therefore wishes to make its further submissions in the matter herein with a view to demonstrating the pervasive and systemic practice of forced and/or coerced sterilization of women living with HIV on the sole ground of their HIV status.

C. THE EXPERIENCES AND IMPACT OF FORCED/COERCED STERILISATION ON WOMEN LIVING WITH HIV

24. The Interested Party's membership consists of women living with HIV around the globe. It has a membership of approximately 15,000 that is spread globally across 120 countries including Kenya.

25. Many of the Interested party's members around the world have unfortunately been victims of sterilization without their informed consent on the basis of their HIV status in the similar manner complained about by the Petitioners herein. Their experiences, legal recourse and remedies sought are well documented by the Interested Party as will be demonstrated shortly through various publications referenced herein below.

a. <u>The lived experiences of stigma, discriminatory practices and human rights abuses arising from forced and coerced sterilization;</u>

26. Across many countries and healthcare settings, women living with HIV report being sterilized without their informed consent during delivery via Caesarean Section or while undergoing other gynecological surgical procedures. Women living with HIV also report being asked or pressured to sign papers or verbally consent to involuntary sterilization under duress, while in labour, often when the women are in pain.[3]

27. Women living with HIV report being asked to consent without being provided accurate information about what they were signing or the procedure and more often than not, were unaware or did not understand

[3] ICWEA REPORT

that they were being asked to agree to tubal ligation which is a permanent and irreversible form of sterilization. [4]Women also report health care workers obtaining consent from their husbands, fathers or other next of kin. Some women who were sterilized without their informed consent during Caesarean Section remain unaware of the violation until such time when undergoing fertility testing due to their struggles to have another child.[5]

28. Women living with HIV are also repeatedly pressured and coerced into undergoing sterilization as a precondition to access needed nutrition or cash support and services. Misinformation regarding the necessity of sterilization due to their HIV status provided by healthcare providers or an understanding that they will be denied life-saving medicines or treatments if they do not undergo sterilization pressurizes women into thinking they have no alternative options and creates duress.

29. These rights violations occur against a well-documented back drop of pervasive stigma, abuse and discrimination experienced by women living with HIV within healthcare settings. A 2015 World Health Organization (WHO) Statement identifies women living with HIV as group who are particularly likely to experience disrespectful and abusive treatment during maternal health care.[6]

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[4] Lindsay Carniak McLaughlin, The Price of Failure of Informed Consent Law: Coercive Sterilizations of HIV-Positive Women in South Africa, 32 LAW & INEQ. 69 (2014).

[5] Supra note 25;"I feel like half a woman all the time": A qualitative report of HIV positive women's 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

[6] World Health Organization, The Prevention and Elimination of Disrespect and Abuse During Facility-based Childbirth (2015), http://www.who.int/reproductivehealth/topics/maternal_perinatal/ statement-childbirth/en/ [https://perma.cc/E2UH-L7WP]
https://www.who.int/reproductivehealth/topics/maternal_perinatal/statement-childbirth/en/

30. According to a recent report by UNAIDS, health care workers themselves reported the following HIV-related stigma and acts of discrimination against people living with HIV including: *"unwillingness to care for patients living with HIV, provision of a poorer quality of care to patients living with HIV (compared to other patients); disclosure of HIV status without patient permission; and referral of patients with HIV because workers do not want to treat them."*[7]

31. Women living with HIV face hostile, discriminatory and outdated attitudes from healthcare providers[8] particularly as they seek to have children or seek reproductive health care services[9]. The following ill-treatment by healthcare providers has also been reported in the context of their maternal health care: *"Staff neglecting them before, during and after their delivery; Staff abusing them during labour because they had become pregnant; Staff refusing to touch them or their newborn baby; Severe delays before receiving attention; and requests to leave hospital earlier than other women"*[10].

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[7] Confronting discrimination: Overcoming HIV-related discrimination in health-care settings and beyond. Geneva: UNAIDS; 2017 Availablehttps://www.unaids.org/sites/default/files/media_asset/confronting-discrimination_en.pdf

[8] "Women reported judgmental provider attitudes, assumptions, involuntary disclosure (exposing women to further forms of violence from partners, family and community members), and breaches of confidentiality." Building a safe house on firm ground: key findings from a global values and preferences survey regarding the sexual and reproductive health and human rights of women living with HIV. Salamander Trust (2014). WHO, Geneva. Available at http://salamandertrust.net/wp-content/uploads/2016/09/BuildingASafeHouseOnFirmGroundFINALreport190115.pdf . Last accessed February 13, 2021.

[9] Early Infant Diagnosis, Understanding the perceptions, values and preferences of women living with HIV in Kenya, Namibia and Nigeria, ICW & GNP+, 2015 Available at https://www.wlhiv.org/knowledge-generation-and-sharing Last Accessed February 13, 2021.

[10] Conf

32. These negative and harmful attitudes in the context of exercising their sexual and reproductive rights result in a host of human rights violations including mandatory HIV testing and coercive treatment practices,[11] a lack of informed consent,[12] stigma, discrimination and even physical abuse at the hands of healthcare providers, forced and coerced sterilization and abortion[13], and refusals to provide family planning or other services.

33. The Global Commission on HIV and the Law has found that women living with HIV around the world face *"coercive and discriminatory practices in health care settings, including forced HIV testing, breaches of confidentiality and the denial of health care services, as well as forced sterilizations and abortions."* [14]

34. A 2008 report by the Center for Reproductive Rights and Federation of Women Lawyers–Kenya[15] found that "Kenyan women living with HIV experience both gender- and health-based discrimination in their access to medical care." *The report documents "coercive practices and violations of informed consent and confidentiality in testing for HIV during*

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[11] Matheson R et al. Journal of the International AIDS Society 2015, 18(Suppl 5):20286

http://www.jiasociety.org/index.php/jias/article/view/20286 | http://dx.doi.org/10.7448/IAS.18.6.20286.

[12]Supra Note 1.

[13]"Once diagnosed, women also reported denial of treatment (especially fertility treatment) or being forced or coerced into services they did not freely choose, including abortion or sterilization."Salamander Trust (2014).Building a safe house on firm ground: key findings from a global values and preferences survey regarding the sexual and reproductive health and human rights of women living with HIV. Salamander Trust (2014). WHO, Geneva.. Available at http://salamandertrust.net/wp-content/uploads/2016/09/BuildingASafeHouseOnFirmGroundFINALreport190115.pdf . Last accessed February 13, 2021.

[14] HIV and the Law: Risks, Rights & Health', Global Commission on HIV and the Law Final Report. July 9 2012 Available at http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf. Last accessed February 13, 2021.

[15] At Risk Rights Violations of HIV-Positive Women in Kenyan Health Facilities, Center for Reproductive Rights 2008 Available at: http://reproductiverights.org/sites/crr.civicactions.net/files/documents/At%20Risk.pdf:.

pregnancy or delivery;" and "discrimination at the hands of health-care personnel, many of whom hold negative views of HIV-positive women's sexual activity and child bearing."

35. The report documents that Kenyan health care professionals, despite advances in efforts to prevent vertical transmission, ultimately hold beliefs that women living with HIV should not reproduce[16]. The same report documents that women living with HIV in Kenya are "reprimanded for bearing children or being sexually active, and denied access to contraception, family planning and maternity services." Misinformation abounds and women living with HIV face "scare tactics" and distortions about the risks to themselves and potential children with future pregnancies.[17]

36. The context of stigma and discrimination along with power imbalances makes it very difficult for women to assert their rights when they must engage with the healthcare system for maternal care and delivery. Women who received an HIV diagnosis during prenatal care reported being vulnerable to coercion because of their lack of knowledge and limited time to assimilate the HIV diagnosis, while women who became pregnant after knowing that they were living with HIV were vulnerable because of the stigmatizing normative assumption that they were not "supposed" to get pregnant."[18] A multi-country study in Latin America describes how "asymmetries in access to information and power between women living with HIV and healthcare providers made it difficult for women to resist

[16]Id. page 44.
[17] Rowlands.
[18] 2015 Kendall T et al;

pressure to sterilize". This information is well captured in the 3rd Petitioner's report referred to as GK-001 and titled "Robbed of Choice". The said report has been annexed to the 6th Petitioner's Affidavit sworn by its programme manager known as Gladys Kiio, in support of the Amended Petition herein.

- **Reported prevalence**

37. The forced and/or coercive sterilization of women living with HIV is a practice that is not unique to the 1st, 2nd, 3rd and 4th Petitioners. It is a widespread and persistent global phenomenon that has now been reported by women living with HIV[19] in nearly 40 countries around the world, including in Bangladesh[20], Belize[21] Brazil[22], Cambodia[23], Chile[24], China[25], Democratic Republic of Congo[26], Dominican Republic[27], El Salvador[28],

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[19] Reports of sterilization have either been formally documented or represent documented reports from ICW affiliated networks, women living with HIV and other networks of women living with HIV around the world.

[20] Positive and pregnant – how dare you: a study on access to reproductive and maternal health care for women living with HIV in Asia, (2012) Reproductive Health Matters, 20:sup39, 110-118, DOI: 10.1016/S0968-8080(12)39646-8 Last accessed February 13, 2021.

[21] Belize Stigma Index 2019 Stigma Index for Persons living with HIV. Available at: https://www.stigmaindex.org/wp-content/uploads/2020/12/Belize-SI-Report-2019.pdf, Last accessed February 13, 2021.

[22] Dr F. Oliveira, L. Kerr, A. Frota, A. Nóbrega, Z. Bruno, T. Leitão, C. Kendall & M. Galvão (2007) HIV-positive women in northeast Brazil: Tubal sterilization, medical recommendation and reproductive rights, AIDS Care, 19:10, 1258-1265, DOI: 10.1080/09540120701405411 Last accessed February 13, 2021.

[23] See Positive and Pregnant: How Dare You.

[24] Dignity Denied: Violations of the Rights of HIV-Positive Women in Chilean Health Facilities (2010) Vivo Positivo & the Center for Reproductive Rights. Available at :https://www.reproductiverights.org/document/dignity-denied-download-report. Last accessed February 13, 2021.

[25] See People Living with HIV Stigma Index Asia Pacific Regional Analysis 2011.

[26] Smith D. African women with HIV 'coerced into sterilisation'. The Guardian. 2009. Jun 22 http://www.guardian.co.uk/world/2009/jun/22/africa-hiv-positive-women-sterilisation. Last accessed February 13, 2021.

[27] Dominican Republic : People Living with HIV Stigma Indexhttps://www.stigmaindex.org/wp-content/uploads/2020/01/Dominican-Republic-SI-Report-2019.pdfLast accessed February 13, 2021.

[28]Kendall, T., & Albert, C. (2015). Experiences of coercion to sterilize and forced sterilization among women living with HIV in Latin America. Journal of the International AIDS Society, 18(1), 19462. http://doi.org/10.7448/IAS.18.1.19462; https://cdn2.sph.harvard.edu/wp-content/uploads/sites/32/2014/11/Kendall_ReproRightsViolations_jan27.pdf. Last accessed February 13, 2021.

Fiji[29], Guatemala[30] Honduras[31], India[32], Indonesia[33], Jamaica[34], Kazakhstan[35], Kenya[36], Kyrgyzstan[37] Mexico [38], Moldova[39], Mozambique[40], Namibia[41], Nicaragua[42], Nepal[43], Viet Nam[44], Pakistan[45],

[29] People Living with HIV Stigma Index Asia Pacific Regional Analysis, 2011, Available at: https://www.unaids.org/sites/default/files/media_asset/20110829_PLHIVStigmaIndex_en_0.pdf Last accessed February 13, 2021.

[30] Guatemala Stigma Index 2017, Available at: https://www.stigmaindex.org/wp-content/uploads/2019/11/Guatemala_PLHIV-Stigma-Index-Report_2017_Spanish.pdf Last accessed February 13, 2021.

[31] See Kendall, et al. Experiences of coercion to sterilize and forced sterilization among women living with HIV in Latin America

[32] See Positive and Pregnant: How Dare You.

[33] See Positive and Pregnant: How Dare You.

[34]Jamaican Network of Seropositives and Health Policy Plus. 2020. The People Living with HIV Stigma Index: Jamaica. Washington, DC: Palladium, Health Policy Plus. https://www.stigmaindex.org/wp-content/uploads/2020/06/Jamaica-SI-Report-2020.pdf Last accessed February 13, 2021.

[35] People Living with HIV Stigma Index, Kazakhstan (2017) Available at https://caapl.org/wp-content/uploads/2020/11/kazakhstah_stigma_index_report_eng_17_05_2017.pdf; Last accessed February 13, 2021.

[36] At Risk Rights Violations of HIV-Positive Women in Kenyan Health Facilities, Center for Reproductive Rights 2008 Available at: http://reproductiverights.org/sites/crr.civicactions.net/files/documents/At%20Risk.pdf: Kasiva F, Kiio G.; Last accessed February 13, 2021.

[37]The People Living With HIV Stigma Index Analytical Report Kyrgyzstan Bishkek 2015, Available at: https://caapl.org/wp-content/uploads/2020/11/kyrgyzstan_stigma_index_report_eng_17_05_2017.pdf Last accessed February 13, 2021.

[38] See Kendall, et al. Experiences of coercion to sterilize and forced sterilization among women living with HIV in Latin America

[39] The People Living with HIV Stigma Index Sociological Research, Moldova, 2018 Available at:https://www.stigmaindex.org/wp-content/uploads/2019/11/Moldova_PLHIV-Stigma-Index_2018.pdf Last accessed February 13, 2021.

[40] ICW Southern Africa Regional Network Anecdotal ICW Member Reports.

[41] Southern Africa Litigation Center, ICW, Namibia Women's Health Network and ICW Southern Africa Submission to the Human Rights Committee Regarding the Forced and Coerced Sterilisation of Women Living with HIV/AIDS in Namibia (2015) Available at: https://www.southernafricalitigationcentre.org/2015/04/25/submission-to-the-hrc-on-coerced-sterilisation-in-namibia/ ;Last accessed February 13, 2021.

[42] See Kendall, et al. Experiences of coercion to sterilize and forced sterilization among women living with HIV in Latin America

[43] See Positive and Pregnant: How Dare You.

[44] See Positive and Pregnant: How Dare You.

[45] See People Living with HIV Stigma Index Asia Pacific Regional Analysis, 2011 http://reliefweb.int/sites/reliefweb.int/files/resources/protecting-rights-of-key-hiv-affected-wg-health-care-settings.pdf

Papua New Guinea[46], Peru[47] ,Philippines[48], South Africa[49], Sierra Leone[50] Sri Lanka[51], Swaziland[52], Tajikistan[53], Tanzania[54], Thailand[55], Uganda[56], Ukraine [57]Venezuela[58], and Zambia[59].

38. Despite differences of geography, religion, culture and language, the experience and stories of women living with HIV who have been subjected to coercive or forced sterilization follow an undeniably similar pattern.

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[46] Maura Elaripe: "I was forced to go through sterilisation and up to now I regret it." IRIN, .http://www1.irinnews.org/hov/79697/papua-new-guinea-maura-elaripe-i-was-forced-to-go-through-sterilisation-and-up-to-now-i-regret, (2018) Last accessed February 13, 2021.

[47] Peru People Living with HIV Stigma Index 2018 Available at:, https://www.stigmaindex.org/wp-content/uploads/2019/11/Peru_PLHIV-Stigma-Index-Report_2018.pdf Last accessed February 13, 2021.

[48] See People Living with HIV Stigma Index Asia Pacific Regional Analysis, 2011

[49] Strode,Mthembu & Essack (2012) "She made up a choice for me": 22 HIV-positive women's experiences of involuntary sterilization in two South African provinces, Reproductive Health Matters, 20:sup39, 61-69, DOI: 10.1016/S0968-8080(12)39643-2 Last accessed February 13, 2021.

[50] Sierra Leone People Living with HIV Stigma Index (2020), Available at: https://www.stigmaindex.org/wp-content/uploads/2020/10/Sierra-Leone-SI-Report-2020_English.pdf Last accessed February 13, 2021.

[51] See People Living with HIV Stigma Index Asia Pacific Regional Analysis, 2011

[52] Member Network Swaziland Network for People Living with HIV/AIDS (SWANEPHA) Swaziland Stigma Index; HIV Stigma Still a Barrier available at http://www.irinnews.org/report/96761/swaziland-hiv-stigma-still-a-barrier

[53]People Living with HIV Stigma Index, Tajikistan (2017) https://caapl.org/wp-content/uploads/2020/11/tajikistan_stigma_index_report_eng_17_05_2017.pdf

[54]United Nations Human Rights: Office of the High Commissioner, Busting the myth that sterilization can end AIDS http://www.ohchr.org/EN/NewsEvents/Pages/ForcedSterilization.aspx Last accessed February 13, 2021.

[55] See also People Living with HIV Stigma Index Asia Pacific Regional Analysis, 2011. Last accessed February 13, 2021

[56] ICW East Africa Violation of Sexual and Reproductive Health Rights of Women Living With HIV in Clinical and Community Settings in Uganda, Available at: http://www.icwea.org/wp-content/uploads/downloads/2015/11/ICWEA-Sexual-Reproductive-Health-Rights-Report-Uganda.pdf ; Last accessed February 13, 2021.

[57] PLHIV Stigma Index 2.0 report from Ukraine 2020. Available at https://www.stigmaindex.org/country-report/ukraine/ Last accessed February 13, 2021.

[58]*Ertürk, YakinReport of the Special Rapporteur on violence against women, its causes and consequences, United Nations Economic and Social Council* 17 January 2005 E/CN.4/2005/72 , Citing to International Council of AIDS Service Organizations (ICASO), In-country Monitoring of the Implementation of the Declaration of Commitment Adopted at the United Nations General Assembly Special Session on HIV and AIDS - A Four Country Pilot Study (2004) and LACCASO and UNAIDS, Magdalena's Story: The Reproductive Rights of a Street Teenager in Caracas (1999); See also Busting the myth that sterilization can end AIDS Last accessed February 13, 2021.

[59] More sterilizations of HIV-positive women uncovered. IRIN News 30 August 2010 http://www.irinnews.org/report/90337/southern-africa-more-sterilizations-of-hiv-positive-women-uncovered; See also Busting the myth that sterilization can end AIDS Last accessed February 13, 2021.

39. The Interested Party is a founding partner of the People Living with HIV Stigma Index along with the Global Network of People Living with HIV(GNP+) and UNAIDS. The Stigma Index has been conducted more than 100 times which has supported community-based research and peer researchers to explore Stigma and other such studies provide critical insights into the experiences of women living with HIV in accessing prevention of vertical transmission. The Stigma Index reports reveal that beyond the cases that have drawn international attention coercive practices are widespread.

40. In 32 countries women living with HIV reported having been coerced by a health-care professional in the previous 12 months to terminate a pregnancy because of their HIV status the percentage of respondents reporting this ranged from 1-2 % to close to 25% of survey respondents.[60]

41. In Uganda, the people living with HIV (PLHIV) Stigma Index Survey Report indicates that 11% of the women respondents were coerced into sterilization by health care professionals because they were diagnosed HIV-positive.[61]

42. In the Dominican Republic, the Stigma Index revealed that 8 % of women living with HIV surveyed reported being advised not to have a child in the past 12 months, 5 % of women living with HIV reported being pressured by a health care professional to get sterilized, while 3% of women living with HIV surveyed reported actually being sterilized without their consent, comparatively this experience was reported by no men in the survey.

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[60] Confronting discrimination

[61] The People Living with HIV: Stigma Index, Uganda. Kampala: NAFOPHANU [National Forum of People Living with HIV Networks in Uganda] 2013.

43. People Living with HIV Stigma Index Asia Pacific Regional Analysis asked survey respondents whether they had ever been coerced into being sterilized by a health-care professional. In Thailand, 29% of respondents indicated that they had experienced coercion, compared to 19% of respondents in Cambodia, 12% in Bangladesh and 9% in Fiji.

44. People living with HIV Stigma Index Survey conducted in Kenya between December 2009 and March 2010, involved a final sample of 1073 PLHIV from five regions within Kenya, revealed that 28.1% of women survey respondents reported being advised by a health care professional not to have a child, 9.6% reported having been coerced into considering sterilization by a heath care professional since they were diagnosed as HIV-positive; 14.5% (indicated that their ability to obtain ART had been made conditional on the use of certain forms of contraception; and 16 women (2.34%) had felt /been coerced by a health professional into termination of a pregnancy within the past 12 months.[62]

45. Other researches that have also confirmed the prevalence of coercive sterilization in the contest of HIV include:

i. In 2011-2012, the Women's Program of the Asia Pacific Network of People living with HIV (now ICW-Asia Pacific) conducted a study on access to reproductive health services in six countries- Bangladesh, Cambodia, India, Indonesia, Nepal, and Vietnam. The study included a survey of 757 women who were living with HIV. Overall, 228 women (30.1%) said they were encouraged to consider sterilization. Of these, 86 women (37.7%) said they did not have the option to decline. "The majority of recommendations for sterilization (61.4%) came from gynecologists and

[62] NEPHAK, GNP+: PLHIV Stigma Index Kenyan Country Assessment, Nairobi. 2011, : NEPHAKhttps://nephak.or.ke/wp-content/uploads/2020/05/PLHIV-Stigma-Index-Kenya.pdf

HIV clinicians and most respondents (82.6%) believe that the recommendations were made on the basis of their HIV status. There was a significant relationship between whether a woman had a caesarean section and whether she was encouraged to be sterilised; 43.5% of women who gave birth by caesarean section were encouraged to be sterilised compared to 29.9% of women who had normal deliveries".[63]

ii. In a study conducted by The Indonesian Positive Women's Network/Ikatan Perampuan Positif Indonesia (IPPI) found that 14% of respondents had undergone forced or coerced sterilization.[64]

- **Lived Testimony**

46. The following quotes have been gathered from women living with HIV from independent research projects around the world and they illustrate the similarities of the experiences of forced or coerced sterilization of women living with HIV:

i. *"He [the doctor] asks how many kids I have. I say it's the second one. Do I have any knowledge about how risky it would be for me to get another child being HIV-positive?.. Then he said the way he sees it I must be sterilized because it's a risk. "* – ***Woman living with HIV, South Africa***[65]

ii. *During the Caesarean and under the effects of the anaesthesia 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 anaesthesia, she saw*

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[63] *Positive and Pregnant-How Dare You?*,2012, APN+Women of Asia Pacific Network of people living with HIV. Available at :http://www.gnpplus.net/images/stories/Rights_and_stigma/APN_Reproductive_and_Maternal_Health_Report_A4_29_March.pdf

[64] Information on the survey summarized at http://www.womenandaids.net/news-and-media-centre/latest-news/positive-women's-network-takes-action-to-address-v.aspx

[65] Supra note 32.

that her finger was stained with ink. **-Woman living with HIV, Mexico, Latin America Region** [66]

iii. *"I was going for a caesarean section. That was the only thing I had signed for. I don't know the rest, I found that out later when I had gone to [a] gynecologist. I had asked if it is possible for me to have a baby. He said, 'No, you were closed up.' 'In which way, is my womb there?' He said, 'No, the womb is there, you did a tubal ligation.' And that is complicated because the tubes were burned. "* – **Woman living with HIV, South Africa, Southern African Region**[67]

iv. *"My sister took me to the doctor when I was due to give birth. My sister met the doctor and they talked in private. I did not request sterilization but my sister told me the doctor recommended it. I was not given any information about the procedure and I did not have an opportunity to ask any questions. I found out later what was done to me when I went to Joint Clinic Research Centre for a check-up; the machine showed that my fallopian tubes were cut. I had not been told and did not sign a consent form."* – ***Woman living with HIV, Uganda***[68]

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[66] Supra note 34

[67] "She made up a choice for me": 22 HIV-positive women's experiences of involuntary sterilization in two South African provinces

[68] ICW East Africa Violation of Sexual and Reproductive Health Rights of Women Living With HIV in Clinical and Community Settings in Uganda, Available at: http://www.icwea.org/wp-content/uploads/downloads/2015/11/ICWEA-Sexual-Reproductive-Health-Rights-Report-Uganda.pdf ; Last Accessed June 13, 2016.

v. *"The nurses forced me to sign. They asked me more than 3 times and threatened not to perform the cesarean. Because of the pressure, I had no option but to sign."* **--Woman living with HIV, Salvadoran, Latin America Region** [69]

vi. *My fallopian tubes were cut when I was 27 in a government hospital. I was in a bad condition when I was pregnant. They then operated on me. I lost a lot of blood, so they decided to cut my fallopian tubes. I did not know anything about it but my aunt knew. She decided for me. After the operation when I gained consciousness, she told me that they cut my fallopian tubes. She told me I should take care of my baby because I will never give birth again. I wanted to find out why the doctor cut my fallopian tubes without my permission. I told them that I was not aware of what they had done. My husband abandoned me, in the house with my children, so I decided to live with my aunt. The decision that was made pains me so much because these days men want women who can give them children. It was wrong for my aunt to decide for me. Perhaps I would have suggested using better family planning methods.* **– Woman living with HIV, Uganda.**[70]

vii. *"The doctor told me that he was going to sterilize me because of my problem [HIV]. And when I got pregnant, he told me that he had warned me not to have another child because of this problem—so he said, "we're going to sterilize you". – **Woman living with HIV, Nicaragua, Latin America.***

[69] Excerpted from research by Dr. Tamil Kendall: https://cdn2.sph.harvard.edu/wp-content/uploads/sites/32/2014/11/Kendall_ReproRightsViolations_jan27.pdf. Last accessed February 13, 2021.

[70] ICW EA

viii. *"I was going for a caesarean section. That was the only thing I had signed for. I don't know the rest, I found that out later when I had gone to [a] gynecologist. I had asked if it is possible for me to have a baby. He said, 'No, you were closed up.' 'In which way, is my womb there?' He said, 'No, the womb is there, you did a tubal ligation.' And that is complicated because the tubes were burned.* " – **Woman living with HIV, South Africa**[71]

ix. *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 Nam, Asia Pacific Region**[72]

x. *"What is funny is that they use the word "tie". They can never tell you that they will sterilize you. They do not explain to them what exactly sterilization is. So, for her she will not know that she was sterilized. She will think that she was only tied and once she needs another baby, she will be untied. They don't differentiate for them tying the fallopian tubes from cutting them. Cutting is the permanent method of family planning where one does not expect to have a baby again, but tying can give a chance to give birth again. But they don't ex- plain to us exactly what they are going*

[71] "She made up a choice for me": 22 HIV-positive women's experiences of involuntary sterilization in two South African provinces

[72] Supra note 25.

to do so that we know how to decide. – **Woman living with HIV, Uganda**[73]

xi. *"He [the doctor] asks how many kids I have. I say it's the second one. Do I have any knowledge about how risky it would be for me to get another child being HIV-positive?.. Then he said the way he sees it I must be sterilized because it's a risk."* – ***Woman living with HIV, South Africa***

xii. *"They only told me that they will sterilize me because I was HIV-positive and I was never sup- 250 posed to get another child."* – ***Woman living with HIV, South Africa***

xiii. *"They said if I were to have a child again, who would raise it because I was going to die soon."* – ***Woman living with HIV, South Africa***

xiv. *"To some degree I also felt that if I don't sign I'd be disappointing this doctor... who has agreed to help me because others have refused."* – ***Woman living with HIV, South Africa***

xv. *"I was told that if I got another child I would die."* – ***Woman living with HIV, South Africa***

[73] ICW East Africa Violation of Sexual and Reproductive Health Rights of Women Living With HIV in Clinical and Community Settings in Uganda, Available at: http://www.icwea.org/wp-content/uploads/downloads/2015/11/ICWEA-Sexual-Reproductive-Health-Rights-Report-Uganda.pdf ; Last Accessed June 13, 2016.

xvi. *"She had an abdominal problem, but instead of operating on her for the pain, they sterilized her without her consent."* - ***-Woman living with HIV, Mexico, Latin America Region*** [74]

xvii. *"They made me sign this paper after I had collapsed in the toilet."* – ***Woman living with HIV, South Africa***[75]

xviii. *"I was sterilized in 2008 at the age of 29 in a hospital. I went to the hospital to get treatment because my fallopian tubes were causing me pain and I had a bad discharge. The doctor decided to test me for HIV and found that I was HIV positive. I was in a lot of pain and the situation was bad. They told me they were going to clean my womb. They took me to the examination room and asked me how many children I had. I told them I had four. They were using English. I did not understand what they were saying because I never studied English. They told me they were going to give me treatment. Later when I gained consciousness I saw a plaster on my stomach, but because I was in great pain, I couldn't ask questions. They gave me drugs to take and told me I would be fine and that if I get any problem I should come back. After sometime, I wanted to reproduce but I was not conceiving and I went to another hospital where they told me my fallopian tubes had been cut. Yet the hospital doctor did not tell me that they had sterilized me. I felt very bad".* – ***Woman living with HIV, Uganda.***[76]

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[74] Supra note 34

[75] Mthembu

[76] ICW EA Report

xix. *"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 Salvador, Latin America Region*** [77]

47. Further illustrations are from the 6th Petitioner's publication titled "Robbed of Choice report" on women living with HIV in Kenya which has also documented experiences of both forced and coerced sterilization which include:

i. *"This was because they said that if it does not happen they will not give me milk for the baby and if I breast feed then the child will become positive. I thought it was true since at that time my CD4 was low and it was risky. I agreed to have the TL done since I could not afford to buy milk for the child. After giving birth in March 2010, I underwent the TL and I was able to get milk from the clinic."* ***-Flo, Kenya***

ii. *"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."* ***-Emma, Kenya***

iii. *"I got to know that I had undergone a tubal ligation when I started having a lot of pain after I regained consciousness. My daughter was by my bedside, and she told me she had heard the doctor say they*

[77] 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.

did tubal ligation on me. They just said it was an emergency and they wanted to save my life and thought it was a good measure to also cut my tubes." ***-Kate, Kenya*** [78].

48. In March 2015 a complaint was submitted by the International Community of Women Living with HIV (ICW) South Africa and Her Rights Initiative (HRI) to the Commission of Gender Equality (CGE) in South Africa[79], a National Human Rights Institution. The complaint was brought on behalf of 48 women living with HIV who were coerced into being sterilised at State Hospitals. Most of the women were pregnant, in labor and were due to give birth through a caesarean section when they were requested to sign a consent form to be sterilised. Some women were led to believe by the healthcare worker that a sterilisation is mandatory for women living with HIV, while other women were told that if they do not sign the consent form they will be denied medical services and others were not provided with an explanation on the nature and consequences of a sterilisation procedure. We provide excerpts from some of the women's sworn affidavits in relation to the stated Complaint to demonstrate the realities women experience at hospitals when interacting with healthcare workers.

[78] Robbed of Choice: Forced and Coerced Sterilization Experiences of women living with HIV in Kenahttps://kelinkenya.org/wp-content/uploads/2010/10/Report-on-Robbed-Of-Choice-Forced-and-Coerced-Sterilization-Experiences-of-Women-Living-with-HIV-in-Kenya.pdf

[79] Complaint Ref No: 414/03/2015/KZN
http://srjc.org.za/wp-content/uploads/2020/03/Forced-Sterilisation-Report.pdf

49. **Complainant A**

"I was in labor and prepared to go to theater. The nurse pushed my bed to theatre. There was a queue at the theatre room and I had to wait outside. At this stage I was extremely anxious, in pain and just wanted to give birth. I focused on remaining calm and taking deep breaths. Approximately, one hour passed before it was my turn to enter the theatre room. After I gave birth to my baby boy through a cesarean (section delivery). I heard the doctor, who was a white male, say "I need to sterilize you now". I never responded to the doctor. I only starred at him. To be honest I did not know what sterilisation meant. Also, the doctor was not asking me a question. He was not asking my consent to be sterilised. He was telling me that he would be sterilizing me. I remember feeling relieved that my baby was born. I was glad the birth was over. I was recovering well after I gave birth and my son was healthy. He was born HIV negative. I was told by a nurse that I could be discharged on Sunday. On the Sunday evening the night nurse said, I should have been discharged today. I told the nurse I didn't know whether I could just get up and leave the Hospital. The nurse said I could leave the following morning. The morning came, I got dressed and before I left the room. The nurse asked to speak to me privately. The nurse asked if the doctor told me that I was sterilised. I replied, yes the doctor said he had to sterilize me. The nurse said ok, you must sign the sterilisation form. The nurse gave me the form and I signed it. I thought this was part of the process of being discharged. After I was discharged I started wondering what sterilisation meant. I started asking people what it meant to be sterilised. Most of the people I asked said that it meant you cannot have children again. I did not tell anyone at that stage that I was sterilised."

50. **Complainant B**

"I was in labor and in serious pain. I am not sure if I passed out but I cannot remember what happened after that. I woke up in a hospital bed in the ward. My sister was sitting by my bedside. The nurse went to fetch my baby and I met my daughter for the first time. My sister left an hour later. Later that day the doctor came to check on me. The doctor told me that the baby was healthy. The doctor said, "We decided to tighten your tubes. It is not permanent. When your weight increases, the clips will undo and you can have children again". I said nothing at that stage. The doctor said, "we had to do it because you are HIV positive". The doctor explained that when my viral load increased, my CD4 count decrease, which placed my health at risk. Therefore, it was best that I did not have children soon after the birth. I was not concerned with what the doctor had told me regarding the tightening of my tubes because the doctor said it was not permanent."

51. **Complainant C**

"After I got admitted and was given a bed, the same doctor who admitted me to the Hospital came to my bedside with my hospital file in his hand. The doctor told me "you are HIV positive". He said, "you will be giving birth through a caesarean section. It is not good to be HIV positive and have babies. What will happen to your child when you die? You know you are going to die if you give birth." I remember taking a deep breath and thinking "I am going to die". I listened to the doctor and I believed him because I know I am HIV positive. I believed him when he said I would die. I was in great pain at the time. I was in so much pain that I felt I was going to die. The pain I was experiencing made it easier for me to believe that I am going to die. The doctor then said, "you are going to be sterilised so that your life won't be in danger. If you have more babies you will die. You are positive and people who are positive should not have children. It

will kill you". The doctor did not ask me if I wanted to be sterilised the doctor told me. The manner in which the doctor explained that I must be sterilised made me believe it was mandatory.

Upon a comprehensive investigation by the CGE who visited 15 State Hospitals they found that the women could not have given informed consent. In this regard the CGE provided that the consent forms do not reflect the nature of the discussions that took place and they are not indicative of the language that was used to explain the procedure. This together with the fact that women were requested to sign the consent forms under extraordinary circumstances and duress led the CGE to conclude unequivocally that signing consent forms do not equate informed consent."

- **Court Cases**

52. Forced and coerced sterilization and principles of informed consent has been the subject of litigation as evidenced by the following;

Namibia

53. The Namibian Women's Health Network in Namibia and the 1st interested party affiliated network first exposed the issue of forced and coerced sterilization in 2008 at a dialogue forum held to listen to younger women. In 2010, as a result of their advocacy and documentation efforts, Namibian women who had been forcibly sterilized filed a suit against the Namibian Ministry of Health and Social Services cited as **Government of the Republic of Namibia v LM and Others (SA 49/2012) [2014] NASC 19**. The Supreme Court of Namibia ultimately "found that the Government of Namibia had breached its duty of care to three women living with HIV who had been forcibly sterilized in a public hospital."[80]

[80] Government of the Republic of Namibia v LM and Others (SA 49/2012) [2014] NASC 19. In: Southern African Legal Information Institute (SAFLI) [website] (http:// www.saflii.org/na/cases/NASC/2014/19.html).

54. The court confirmed that three women living with HIV had been forcibly sterilized without their informed consent during emergency caesarean deliveries. The court also confirmed that the Ministry of Health's duty of care included a duty to ensure that informed consent was obtained prior to all medical treatment. The court's decision obligated the government to take steps to eliminate the practice of forced sterilization.

55. The Namibian case confirms broader global pattern of discrimination and abuse experienced by women living with HIV. The case involved three plaintiffs whose testimony may be summarized as follows;

i. The first plaintiff was 26 years old, pregnant and in labor. While in labor for 14 to 15 hours she was given one form to sign. The form, which she was requested to sign, contained a section for the caesarean procedure and a section for a bilateral tubal ligation. The first plaintiff signed this form while she was on a stretcher waiting to go into theatre. The first plaintiff testified that the nurse informed her that all women who are HIV positive must be sterilised.

ii. The second plaintiff, was in labor and had to give birth via a caesarean. She was requested to sign two forms while she was in labor. The first form contained a section for the caesarean section and tubal ligation. On this form it was indicated that she was giving consent to the caesarean section and the tubal ligation due to her previous caesarean section. She was requested to sign another form, which was for a tubal ligation.

iii. The third plaintiff was 47 years old and had seven children. She was in labor and due to give birth via a caesarean section. She was on a stretcher

waiting for her turn to enter the operation room when she was requested to sign two forms. The first form was a standard form for caesarean section and tubal ligation. In the medical file it stated that she is having a caesarean due to her HIV status; due to her advanced age and the number of previous children. The second form was for a tubal ligation. She signed both forms while in labor.

South Africa

56. The first case in South Africa to confront the issue of coerced and forced sterilization of women was **Sithole v The MEC for Health and Social Development & 3 Others – unreported case no. 19744/2012.**

57. In this matter, Mrs. Sithole was admitted to a maternity unit at a State Hospital on the 31 May 2009. Mrs. Sithole gave birth via cesarean section on the 4 June 2009. Mrs Sithole was then requested to sign forms in respect of which the nurse offered no explanation as to what the forms were, only that they were necessary for her to give birth. One of the forms which she unknowingly signed was a consent form to be sterilized.

58. Naturally, the question arose as to why Mrs. Sithole was given a consent form to be sterilised. At her antenatal consultations she had elected an intrauterine device for her future choice of contraception, not a sterilisation procedure. Mrs Sithole's case was settled outside of court just before the trial date because the State agreed upon a settlement amount. Although a judge did not adjudicate this matter it is worth noting that the matter was settled outside of court whereby Mrs. Sithole received monetary compensation for having been subjected to sterilization without her consent.

b. **The impacts of forced and coerced sterilization on the lives of women living with HIV.**

59. Women living with HIV, like many other women want to have children and raise family.[81] For some women, "this wish to have a family is stronger than before their diagnosis."[82] In addition to their individual reproductive wishes and plans, there is significant pressure coming from family and male partners to reproduce. "Generally, and especially in Africa, a woman's ability to bear children is perceived to be her 'role, purpose and identity'." [83]

60. Forcefully or coercively ending a woman's reproductive capacity by permanent sterilization is a devastating violation of rights that can result in long-term negative psychological and socio-cultural effects including economic and interpersonal impacts. These negative effects include anxiety, stress, fear, isolation, shame, self-blame and feelings of helplessness, hopelessness, worthlessness, anger and sadness, extreme social isolation, family discord or abandonment, fear of medical professionals, and lifelong grief.

61. Menstrual bleeding, severe abdominal pain, severe back pain, weakness and problems with the lower limbs are symptoms experienced soon after the sterilization operation and persist post the procedure. Male partners

[81] Mc Laughlin
[82] Mc Laughlin
[83] MC laughlin

may react to sterilization by withholding money, domestic violence, or abandonment of their spouses.

62. A victim of forced sterilization is quoted to have stated " ... *I was kind of feeling ashamed because, I was thinking that I am no longer a real woman.* " [84]

63. Once sterilized, women are deprived of the possibility of motherhood, which is in itself stigmatizing. In Africa, the stigma associated with the inability to have children is greater than that associated with HIV. Being unable to have children can eliminate marriage prospects, and increase women living with HIV's vulnerability to gender-based violence. Some women reported financial effects such loss of a job and reduced productivity.

64. Inability to have children undermines women's self-worth and severely impacts their identity as women and mothers. This is particularly true in communities and social structures which place a high value on motherhood or stigmatize childlessness. Women who cannot have children are marginalized and experience diminished social status, which can have a negative impact on their mental health and well-being.

65. Majority of these effects have been reffered to and well explained in the expert report of clinical psychologist Elizabeth Khaemba and Psychiatrist Dr. David E. Bukasi in their report titled " Psychological and Psychiatric Evaluation" prepared in respect of the 1st Petitioner. This report is annexed

[84] Kudzai Bakare & Shelene Gentz (2020) Experiences of forced sterilisation and coercion to sterilise among women living with HIV (WLHIV) in Namibia: an analysis of the psychological and socio-cultural effects, Sexual and Reproductive Health Matters, 28:1, 1758439, DOI: 10.1080/26410397.2020.1758439

to the affidavit that the 1st petitioner swore in support of the Amended Petition herein. Indeed the Petitioner confirmed the severe consequences that she has had to deal with when she gave her testimony before the court.

c. Prevention of mother to child transmission of HIV

66. The 1st interested party's submissions would be incomplete without delving into the subject of **Prevention of mother to child transmission of HIV**. Your Lordship will note that in the present petition, the 1st petitioner was told to go to the 1st respondent for her delivery, and told that if she had anymore children, it would compromise her health or even cause her death. In addition, the body of evidence shows that involuntary sterilization of women living with HIV is most often documented in the context of efforts to prevent mother to child transmission of HIV, also known as vertical transmission of HIV.[85]

67. As the global scale-up of the prevention of vertical transmission of HIV efforts continues, women living with HIV, in particular pregnant women and those seeking to become pregnant, play a central role in reaching the shared goals of "getting to zero" children born with HIV. Prevention of vertical transmission practices including access to treatment and prevention practices such as infant prophylaxis which reduces the chances that women living with HIV will vertically transmit HIV during pregnancy, the birth process or during breastfeeding[86].

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[85] Also known as prevention of mother to child transmission (PMTCT).
[86] World Health Organization, Guidance on the Global Scale Up of the Prevention of Mother to Child Transmission (2007).

68. Advances in prevention of vertical transmission have been successful enough that the World Health Organization has begun validating countries around the world for the successful elimination of mother-to- child transmission (EMTCT) of HIV.[87] Notably, validation of these countries can only be granted if the country's prevention of vertical transmission programming also meets with human rights standards, including demonstrating no reported cases of forced or coercive sterilization. Unfortunately, in some programmatic contexts, an over focus on eliminating transmission has led to coercive measures directed at pregnant women living with HIV or those who wish to become pregnant. These coercive measures have been noted to include mandatory prenatal and postnatal testing followed by coerced abortion or sterilization without consent[88]. 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.[89] The types of justifications offered by healthcare workers for these rights violations have been identified as falling into four general areas:

i. The HIV status and socioeconomic circumstances of the women are deemed to influence the healthcare workers as to the women's suitability to bear more children;

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[87] Kismödi, Eszter, et al. "Where Public Health Meets Human Rights: Integrating Human Rights into the Validation of the Elimination of Mother-to-Child Transmission of HIV and Syphilis." Health and Human Rights, vol. 19, no. 2, 2017, pp. 237–247. JSTOR, www.jstor.org/stable/90016129. Accessed 19 Mar. 2021.

[88] Confronting Discrimination

[89] 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. Last accessed February 13, 2021.

ii. Healthcare workers see sterilization as a means to preventing children being born HIV-positive;

iii. Some healthcare workers believe that this practice avoids children being left motherless or orphaned;

iv. Some healthcare workers argue that HIV-positive women should not expose themselves to harm by carrying a child.

69. These stigmatizing and discriminatory justifications for violations of women rights, are based on a lack of respect for women's autonomy, agency, and well-being, misinformation, discriminatory and paternalistic attitudes and stigmatizing. Critically, flawed justifications such as these are unacceptable as public health rationales anywhere in the world.

70. Prevention of vertical transmission goals can never justify violations of women's human rights. Forced and coerced sterilization is under no circumstances a legitimate method of prevention of vertical transmission. Sterilization is not an emergency procedure that justifies suspension of rights to informed consent.

A. CONCLUSION

71. Forced and coerced sterilization is part of a pattern of HIV related stigma and discrimination experienced by women living with HIV in Kenya and elsewhere. Sterilization of women living with HIV without informed consent and/or under coercion is a form of institutionalized violence and a persistent practice of human rights violations, which forms part of a systemic pattern of discrimination against women living with HIV.

72. Women living with HIV who experience forced or coerced sterilization have experienced a severe violation of their human rights that causes irreparable harm, stripping them of their reproductive capacity without their consent. The practice of forced and/or coerced sterilization of women living with HIV is damaging, humiliating, irreversible, and medically unnecessary.

73. The outcome of this suit will have a significant impact on the lives of women living with HIV, not just in Kenya but around the world and could have a powerful positive effect on the efforts of women living with HIV in the Interested party's member networks around the world working to end the practice of forced and coerced sterilization including at the national, regional and global levels.

74. Owing to the intersectional discrimination (individual, systemic and institutional) on various grounds such as race, gender, HIV status, socioeconomic status – there is a need for a strong non-discriminatory approach to be taken in addressing this practice. *"Once a court finds that the sterilisation is due to discriminatory practices, it can change the issue from one of a few bad incidents to one requiring structural reform".*[90]

75. A finding of discrimination by this honorable court is important because it allows for the problem of forced and coerced sterilization to be addressed on a structural level thus paving way for national reforms.

[90] Patel, P. Forced sterilization of women as discrimination. Public Health Rev 38, 15 (2017). https://doi.org/10.1186/s40985-017-0060-9

76. This court has a unique opportunity to be part of global judicial leadership in condemning this practice and securing justice for women living with HIV who have experienced this kind of rights violation. Providing a satisfactory resolution to the issue raised including holding practitioners accountable, ensuring compensation and justice to the victims is critical, **without these steps** "governments are breaching their obligations to uphold human rights."[91]

77. We submit in support of the Petitioners' Amended Petition dated 10th September 2015 and urge the Honourable court to allow the same in entirety.

DATED at Nairobi this 7th day of July 2021

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[91] Against Her Will, Open Society Foundations available at http://www.opensocietyfoundations.org/publications/against-her-will-forced-and-coerced-sterilization-women-worldwide

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