

Technical Brief Fulfilling the sexual and reproductive rights of women living with HIV, preventing coerced and forced sterilization

Introduction

With all the knowledge and scientific progress in a forty-year-old HIV pandemic, it is unacceptable that all women living with HIV in all places and their partners cannot fulfill their sexual and reproductive rights.

In 1994, at the International Conference on Population and Development (ICPD), 179 countries adopted a Programme of Action that recognized that reproductive rights are human rights. The ICPD Programme of Action defines reproductive health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and its functions and processes."¹ The right to health includes the "right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation."^a Human rights standards recognize that women living with HIV have a right to reproductive health services on the same grounds as all other women, and that the fulfilment of reproductive rights requires healthcare providers to be non-coercive and to respect autonomy, privacy and confidentiality.^a Realization of sexual and reproductive health and rights implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so.^a

Over the past thirty years, scientific advances and increasing availability of combination antiretroviral therapy (ART) has promoted the health and well-being of people living with HIV, including by providing more options for women living with HIV and their partners to prevent pregnancy, Technical Brief: Fulfilling the sexual and reproductive rights of women living with HIV, preventing coerced and forced sterilization

safely conceive and have healthy pregnancies. A cornerstone of these scientific advances is that people living with HIV who are taking combination ART and who are virally suppressed (plasma viral load <50ml) do not transmit the virus either to sexual partners^v or to their offspring during pregnancy and childbirth.^{vi} This is known as "Undetectable = Untransmittable".^{vii}

Yet, despite human rights guarantees and scientific progress that increases options for fulfilling sexual and reproductive rights, HIVrelated stigma and discrimination continue to drive sexual and reproductive rights violations. One of the most extreme reproductive rights violations and expressions of HIV-related stigma and discrimination is coerced and/or forced sterilization¹ of women living with HIV.

Purpose of this technical brief

The purpose of this technical brief is to promote gender-transformative, rights--based and scientifically accurate information for advocacy and service-delivery to fulfill the sexual and reproductive rights of women, girls and people who have the capacity to become pregnant², who are living with HIV.

In doing so, we also aim to provide sufficient evidence to prevent sexual and reproductive rights violations, especially coerced and/or forced sterilization against those living with HIV.

The technical brief documents that coerced and/or forced sterilization of women living with HIV is a persistent and serious human rights violation requiring urgent action. The brief reviews components of comprehensive sexual and reproductive health (SRH) service delivery and international medical guidance to uphold and fulfill the sexual and reproductive health and rights of women living with HIV to choose if and when to have children.

This brief is primarily intended to inform IPPF Member Associations, secretariat staff, and partners including other SRH service delivery organizations and stakeholders. The brief reinforces IPPF's position and commitment to person-centred and rights-based HIV care that is integrated within a comprehensive package of SRH services.

Coerced and/or forced sterilization of women living with HIV is a serious and persistent reproductive rights violation

Sterilization without full, free and informed consent is recognized by international, regional and national human rights bodies as an involuntary, coercive and/or forced practice, and as a violation of fundamental human rights. Coerced and/or forced sterilization violates the right to health, the right to information, the right to privacy, the right to decide on the number and spacing of children, the right to form a family and the right to be free from discrimination. Human rights bodies have also recognized that forced sterilization is a violation of the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.^{ix}

Coerced and/or forced sterilization of women living with HIV has been documented in multiple regions and is of global concern.xxixii,xii,xiv,xv Coerced and/or forced sterilization of women living with HIV by healthcare providers commonly occurs

¹ Coerced sterilization occurs when misinformation, intimidation tactics, incentives (financial or other) are used to compel an individual or when sterilization is made a condition of access to health services, employment or other benefits. Forced sterilization occurs when an individual is sterilized without their knowledge or consent. Open Society Foundation. Against her will: forced and coerced sterilization of women worldwide. New York: Open Society Institute, 2011. https://www.opensocietyfoundations.org/uploads/62505651-2c58-4c12-a610-46499e645a2c/against-her-will-20111003.pdf ² This document is inclusive of women and girls and all people who can become pregnant, including intersex people, transgender men and boys and people with other gender identities that may have the reproductive capacity to become pregnant. For the purposes of this document, references to "women and girls" refer to all people who have the capacity to become pregnant.

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at the time of delivery via caesarean section. At the time of caesarean section, women report that healthcare providers coerced them into accepting sterilization by making discriminatory and medically unfounded statements about HIV, by withholding medical care, by threatening to withhold benefits, treatment and financial supports, or conducted the sterilization without women's knowledge or consent.xvi A study in five Latin American countries showed that having a pregnancy with a known HIV diagnosis resulted in a six-fold increase in the risk of coercion to sterilize or forced sterilization among women living with HIV as compared to women living with HIV who did not have a pregnancy after the diagnosis.xvii In addition to the violation of bodily integrity, women living with HIV report serious negative mental health consequences of coerced and/or forced sterilization (such as anxiety and depression), further stigma and discrimination as a consequence of not being able to bear children and other negative impacts on their social and cultural well-being.xvii, xix

Despite advocacy by women living with HIV and human rights defenders over two decades, and several court cases that have recognized and sanctioned coerced and forced sterilization of women living with HIV, xx, xxi this serious human rights violation persists. For example, in 2020, community-based research in Honduras found that a guarter of the women living with HIV interviewed (20 of 78) had been sterilized without informed consent at the national public referral hospital.xii In 2020, the Joint United Nations Programme on HIV/AIDS (UNAIDS) stated that more needs to be done to fulfill the commitment made by the United Nations General Assembly in the 2016 Political Declaration on Ending AIDS to end forced sterilization of women living with HIV.xxiii

The accounts of women living with HIV who have been subjected to coerced and forced sterilizations make it clear that healthcare providers are motivated by HIV-related stigma and discrimination, and beliefs that are not informed by up-to-date scientific evidence about prevention of HIV transmission.xxiv HIV-related stigma is compounded by gender discrimination and social norms on the basis of which women are judged "worthy" of raising a child.xxv, xxvi Racialization, ethnicity, disability status and socioeconomic determinants are additional lavers of the intersectional stigma and discrimination that increase women's vulnerability to being exposed to coerced and/or forced sterilizationxxvii, xxviii, xxix, xxx Gender transformative approaches that challenge harmful gender norms and unequal power relationships and increase women's autonomous decision-making and access to resources are needed to address intersectional discrimination. prevent forced and/or coerced sterilization and fulfill the sexual and reproductive rights of women living with HIV.

Ending HIV criminalization, defined as the application of criminal and similar laws specifically to HIV transmission, is one component of a gender-transformative and rights-promoting approach. Criminalization negatively affects women, increases HIV-related gender-based violence, reinforces HIV-related stigma and discrimination, undermines efforts to prevent new cases of HIV and is contrary to a rights-based approach.xxxi, xxxii Criminalization is a major barrier to creating an enabling environment for women living with HIV to access comprehensive SRH care and education.xxiv International human rights bodies recommend the removal of HIV-specific criminal laws and UNAIDS states that criminal law should "never apply to vertical transmission, including breastfeeding."xxxv

Gender-transformative, rights promoting approaches in communication, advocacy and service delivery informed by the best science and aligned with international medical guidelines can contribute to ending HIV-related stigma and discrimination in policy and practice and fulfilling the sexual and reproductive rights of women living with HIV and their partners.

Comprehensive sexual and reproductive health services for women living with HIV

Since the 2004 Glion Call to Action, the United Nations and international experts have recognized that strengthening policy and programmatic linkages between reproductive health and HIV is necessary to respond to HIV and AIDS among women and children, including by preventing unintended pregnancies among women living with HIV, preventing vertical transmission of HIV, and providing care, treatment and support for women living with HIV and their families.xxxvi In 2018, the need and potential for integration of SRH and HIV services, particularly at the primary care level, to better meet all peoples' rights to receive comprehensive health services free from stigma and discrimination and advance towards the achievement of Universal Health Coverage and the Sustainable Development Goals was reiterated by WHO and UNFPA, and endorsed by multiple agencies including IPPF.xxxvii Overall, integration of HIV and SRH services is associated with increased provision of information and counselling, increased uptake of SRH and HIV services and can improve accessibility and quality while reducing HIV-related stigma.xxxviii

All women living with HIV should have access to integrated and comprehensive SRH services which includes antenatal, perinatal, postpartum and newborn care; high-quality contraceptive services, and infertility care; safe abortion care; prevention and treatment of sexually transmitted infections including HIV, reproductive tract infections, cervical cancer and other gynaecological morbidities; and promotion of sexual health.xxxxx. * This comprehensive package of SRH services is aligned with IPPF's essential package of SRH care.

International and national medical guidance on pregnancy prevention, safer conception and prevention of HIV vertical transmission for women living with HIV and their partners

The science of undetectable=untransmittable supports the choices of women living with HIV and their partners regarding safer conception, pregnancy and mode of delivery (vaginal or caesarean section). This section provides a brief overview of international guidance on comprehensive SRH for women living with HIV, focusing on contraceptive options, safer conception guidelines and feasibility research, and prevention of vertical HIV transmission. The realization of the sexual and reproductive rights of women living with HIV and their partners is supported by the available science, feasible in a wide range of healthcare delivery settings and should be systematically adopted and normalized in the provision of services, reducing HIV-related stigma and discrimination, and preventing sexual and reproductive rights violations.

Pregnancy prevention

Women living with HIV who want to prevent pregnancy are medically eligible for and should be able to choose from a full range of contraceptive methods, including male and female condoms and hormonal contraception (taking into consideration antiretroviral treatment regimen and disease stage).^{xii} Assuring voluntary, informed choice is an important principle for all contraceptive counselling.^{xii}

If they desire a *permanent* contraceptive method, women living with HIV are also medically eligible for surgical sterilization, though the presence of an AIDS-related illness may require that the procedure be delayed. The medical eligibility guideline for contraception emphasises that for sterilization, careful counselling about the intended permanence and awareness of the availability of alternative, long-term and highly effective methods is particularly important. For young people, people who do not have children, and clients with mental health challenges additional diligence is necessary to ensure that the procedure is voluntary and understood as completely as possible by the person undergoing it.*** The timing of counselling and decision-making about sterilization is relevant. Counselling during pregnancy and decision-making before labour and delivery is an internationally recommended good practice to facilitate truly informed consent and reduce the likelihood of regret

about sterilization.^{xiv} For abortion-seeking clients, counselling and decision-making should not take place at the time of the abortion counselling and procedure.

Safer conception

In 2021, WHO stated that contraception services, safer conception management and links to antenatal care should be available when providing pre-exposure prophylaxis (PrEP) services for women and transgender men.^{xiv} The most recent guidelines for antiretroviral management during pregnancy from the Department of Health and Human Services (HHS) Panel on Treatment of HIV During Pregnancy and Prevention of Perinatal Transmission in the United States of America (December 2021) provides specific guidance for people who want to conceive when one or both partners are living with HIV. This includes the person(s) living with HIV achieving viral suppression (less than 50 copies/ml) and screening for genital tract infections before having condomless sex. To increase probability of conception, intercourse can be timed with ovulation. The guidelines also recommend that people consider the use of PrEP if viral suppression is not achieved. This could happen in instances where there are concerns about antiretroviral adherence of one or both of the partners living with HIV; if the HIV status is unknown; or if the HIV-statuses of the partners are different.xivi Though not as recent as the guidelines from the HHS in the United States of America, other countries that have integrated safer conception services into their national guidelines for HIV or reproductive health include Botswana, Canada, and South Africa. It is also important to note that civil society organizations and networks of women living with HIV have decades of experience providing peer education to support safer conception.xivii

Feasibility studies from Kenya and South Africa have shown that safer conception services can be delivered in primary care settings. Nurse-delivered safer conception services included: counselling on fertility desires and intentions, education about ovulation and the fertile period, and condomless sex; ART for partners living with HIV and PrEP for the HIV-negative partner and/or provision of syringes for self-insemination. There has been high-uptake of these services by people living with HIV and their partners, and implementation has demonstrated that safer conception is feasible, with no cases of vertical or sexual HIV transmission.xiviji, xiix

Prevention of vertical HIV transmission

Since 1996, taking ART during pregnancy has been shown to reduce vertical HIV transmission and, since the mid-2000s, combination ART (which lowers the pregnant woman's viral load) has shown to reduce HIV vertical transmission rates to between 1-4%.¹ The probability of vertical HIV transmission is close to zero for women living with HIV who are taking ART at the time of conception and throughout pregnancy and are virally suppressed at the time of delivery.¹¹

For women who do not know their HIV status when they become pregnant, testing for HIV, together with syphilis and hepatitis B surface antigen, at least once and as early in pregnancy as possible is recommended. For all people, WHO recommends initiation of ART regardless of WHO HIV clinical stage and at any CD4 cell count, and on the same day that HIV diagnosis is confirmed for people who are ready to start. Urgent initiation among pregnant and breastfeeding women living with HIV is recommended because the most effective way to prevent HIV vertical transmission is to reduce maternal viral load.^{III}

The science of undetectable=untransmittable also supports the choices of women living with HIV regarding mode of delivery (vaginal or caesarean section). WHO states that elective caesarean section should not be routine for women living with HIV.^{III} Benefits and risks of different modes of delivery should be discussed and, as for all women, when indicated for other medical or obstetric reasons, caesarean section should be offered.^{IIV} Technical Brief: Fulfilling the sexual and reproductive rights of women living with HIV, preventing coerced and forced sterilization

ART significantly reduces but does not completely eliminate the possibility of infant HIV acquisition through breastfeeding. WHO Guidelines (2021) recommend that women living with HIV initiate breastfeeding, while being fully supported for ART adherence.^w Non-judgemental, evidence informed, patient-centered counselling that addresses women's social, cultural and economic situation and personal preferences as well as the health benefits of breastfeeding and potential for infant HIV acquisition is needed to support women living with HIV to make informed choices in all settings.^{IM}

WHO GOOD PRACTICE STATEMENT ON ART INITIATION "ART initiation should follow the overarching principles of providing people-centred care. Peoplecentred care should be focused and organized around the health needs. preferences and expectations of people and communities, upholding individual dignity and respect, especially for vulnerable populations, and should promote engaging and supporting people and families to play an active role in their own care by informed decision-making. People should be encouraged but not coerced to start ART immediately and should be supported in making an informed choice regarding when to start ART and what ARV drug regimen to use."^{lvii}

Recommendations

IPPF Member Associations and other SRH service delivery organizations and stakeholders can engage in the following actions to fulfill the sexual and reproductive rights of women living with HIV and contribute to preventing coerced and/or forced sterilization.

Communication

- Increase awareness of the science underpinning prevention of HIV transmission (undetectable = untransmittable).
- Promote awareness of the most recent and up-to-date international, regional and national HIV treatment and care guidelines.
- Engage with networks of women living with HIV and national-level technical working groups to determine if and to what extent national governments need to update their national service delivery guidelines to support integrated service provision for comprehensive SRH care for women living with HIV. This should include providing a range of contraceptive options, safe and voluntary abortion, safer conception services and integration of ART treatment into maternal and child health services (in high HIV burden settings) or provider-assisted referral to support access to ART and HIV care and treatment (in low HIV burden settings).

Advocacy

- Support organizations and networks of women living with HIV that are promoting their sexual and reproductive rights and access to comprehensive SRH services.
- Advocate for the sexual and reproductive rights of women living with HIV, in collaboration with people living with HIV organizations and networks.
- Raise the ongoing issue of coerced and/or forced sterilization of women living with HIV at decision-making tables and advocate for improved accountability of governments, health systems and health professionals to prevent and ensure redress for rights violations.
- Promote clients' right to informed decision-making as a human rights principle when providing any SRH information and services.

- Promote gender-transformative approaches to sexual and reproductive health programs and policies. Gender transformative programs and policies seek to change harmful gender norms and unequal power relationships and increase girls and women's autonomous decisionmaking and access to resources.
- Advocate at national and regional levels, to legislative bodies and ministries of health, to create an enabling environment for comprehensive and integrated SRH services, including by opposing criminalization of HIV transmission and other laws and policies that stigmatize and discriminate against populations living with and affected by HIV.
- Promote countries joining the UNAIDS Global Partnership for Action to Eliminate all Forms of HIV-related Stigma and Discrimination.^{Mill}

Service Delivery

Service providers should always:

- Prioritize a client-centred, gender-transformative, and rights-based approach to comprehensive SRH service provision.
- Help sexually active individuals make informed decisions by providing accurate and complete SRH information.
- Ensure informed consent. For permanent contraceptive methods, particular care is warranted. Women's informed decision making about sterilization should occur prior to entering the healthcare setting for either abortion or delivery services.
- Support people living with HIV to achieve their reproductive goals by providing comprehensive, stigma-free SRH counselling that addresses contraception, safer conception, safe abortion and safe pregnancy. This should include information on undetectable=untransmittable and how to safely achieve pregnancy (including for people with subfertility or infertility) and to prevent sexual and vertical HIV transmission.

Actions to ensure quality service delivery include:

Training and workshops to address service

provider stigma and discrimination against women living with HIV and to emphasize the fundamental guiding principals of promoting human rights and gender equality.

- Assess the status and availability of comprehensive SRH services at Member Association facilities to ensure that service provision includes an integrated package of SRH care. Assessments can include determining human resource training needs; HIV and contraceptive commodity availability (including PrEP); availability of integrated data recording and management system that ensures client confidentiality; and the availability and use of job aids and other materials that support comprehensive service provision.
- Provide accurate and comprehensive HIV/ STI and other SRH information and services to all people seeking SRH services. This includes counselling on dual protection for preventing both unintended pregnancy and STIs, provision of male/external and female/ internal condoms and lubricants, antiretroviral prevention (PrEP and PEP), harm reduction interventions (e.g. sterile injection equipment) and prevention and management of co-infections and other co-morbidities.
- Provide accurate and comprehensive information about undetectable=untransmittable. Ensure that all people living with HIV are familiar with this information.
- Provide specific information, training, and monitoring of service delivery or referral of women living with HIV and their partners for rights-affirming, stigma free services to reach their reproductive goals. These services should include: 1) contraceptive services, 2) safer conception services 3) abortion care and 4) prevention of vertical HIV transmission. Prioritize client-centred, gender-transformative support and retention in care and treatment post-delivery.
- Women living with HIV should be supported to make informed decisions about infant feeding through non-judgmental, evidence

informed counselling. In low and middleincome countries, WHO recommends that all women, including women living with HIV, breastfeed for at least 12 months; shorter durations of breastfeeding (less than twelve months) is considered preferable to never initiating breastfeeding at all. Practising mixed feeding is not a reason for women living with HIV to stop breastfeeding in the presence of ARV drugs.

Conclusion

It is time to step-up our efforts to ensure that women living with HIV and their partners can fulfill their sexual and reproductive rights. The science and human rights standards are clear. Yet, women living with HIV continue to face ignorance, stigma and discrimination when seeking sexual and reproductive health services and experience rights violations. Among the persistent sexual and reproductive rights violations experienced by women living with HIV is coerced and/or forced sterilization.

Networks of women living with HIV and HIV organizations around the globe are active proponents of sexual and reproductive health and rights. IPPF Member Associations and likeminded organizations have a critical role to play in promoting, protecting and fulfilling the sexual and reproductive rights of people living with HIV through evidence- and rights-based advocacy and service delivery.

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^{IIIV} WHO. 2017. Consolidated Guideline on sexual and reproductive health and rights of women living with HIV. Geneva: WHO: 64-65.

¹WHO. 2021. Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring. Geneva: 298-301. Mothers living with HIV should breastfeed for at least 12 months and may continue breastfeeding for up to 24 months or longer (similar to the general population). Women and healthcare providers should be counselled that although exclusive breastfeeding is recommended, practising mixed feeding is not a reason to stop breastfeeding in the presence of ARV drugs. Shorter durations of breastfeeding (less than 12 months) are better than never initiating breastfeeding at all.

^{Ivi} In high-income settings, some medical guidelines are providing guidance for balanced counselling on infant feeding. See for example, the British HIV Association (BHIVA) guidelines for the management of HIV in pregnancy and postpartum 2018 (2020 third interim update). <u>https://www.bhiva.org/file/5f1aab1ab9aba/</u> Technical Brief: Fulfilling the sexual and reproductive rights of women living with HIV, preventing coerced and forced sterilization

BHIVA-Pregnancy-guidelines-2020-3rd-interim-update.pdf.

Accessed June 13, 2022. Networks of women living with HIV are also developing guidance and educational materials to support informed decision-making about infant feeding in high-income settings. See for example 4MNetwork. 2020. "Infant Feeding for Women Living with HIV", https://4mmm.org/resources/ infant-feeding-for-women-living-with-hiv/; The Well Project. 2021. "Can I breastfeed while living with HIV? An overview of infant feeding options" <u>https://www.thewellproject.org/hivinformation/can-i-breastfeed-while-living-hiv-overview-infantfeeding-options</u>. Accessed June 13, 2022.

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Who we are

The International Planned Parenthood Federation (IPPF) is a global service provider and a leading advocate of sexual and reproductive health and rights for all. We are a worldwide movement of national organizations working with and for communities and individuals.

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