



Swiss Initiative to Commemorate the 60th Anniversary of the UDHR

*Protecting Dignity: An Agenda for Human Rights*

RESEARCH PROJECT ON RIGHT TO HEALTH:

**“Addressing the reproductive health rights of women living with HIV in Southern Africa”**

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The year 2008 marked the 60th Anniversary of the Universal Declaration of Human Rights. To commemorate this occasion, and in order to make a meaningful contribution to the protection of human rights, the Swiss Government decided to launch "An Agenda for Human Rights". The initiative aims to explore new ways of giving human rights the weight and place they deserve in the 21st century. It is designed as an evolving and intellectually independent process.

The text *Protecting Dignity: An Agenda for Human Rights* was authored by a Panel of Eminent Persons, co-chaired by Mary Robinson and Paulo Pinheiro. This *Agenda* and the Swiss Initiative are designed to achieve two objectives: firstly, to set out some of the main contemporary challenges on the enjoyment of human rights, and secondly, to encourage research and discussion on a number of separate topics linked to the *Agenda*. These include: Human Dignity – Prevention – Detention – Migration – Statelessness – Climate Change and Human Rights – the Right to Health – and A World Human Rights Court.

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# **Realising the right to health in the Universal Declaration of Human Rights after 60 years: addressing the reproductive health rights of women living with HIV in Southern Africa**

**A project by the Centre for Human Rights, University of  
Pretoria, for the Swiss Initiative to Commemorate the 60th  
Anniversary of the Universal Declaration of Human Rights -  
Protecting Dignity: An Agenda for Human Rights**

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## **ACKRONYMS**

ACHPR	African Charter on Human and Peoples' Rights
AIDS	Acquired Immune Deficiency Syndrome
CEDAW	Convention on the Elimination of all Forms of Discrimination against Women
CBOs	Community based organizations
CERS	Committee on Economic, Social and Cultural Rights
CRC	Convention on the Rights of the Child
FIGO	International Federation of Gynaecology and Obstetrics
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV/AIDS
ICPD	International Conference on Population Development
ICESCR	International Covenant on Economic, Social and Cultural Rights
MDG	Millennium development goals
MSF	<i>Medecins sans Frontiers</i>
MTCT	Mother to child transmission
NGO	Non-governmental organisation
PITC	Provider-initiated testing and counselling
PMTCT	Prevention of mother to child transmission
PPT	Prevention of perinatal transmission
SADC	Southern Africa Development Community
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNC	University of North Carolina Project
WHO	World Health Organisation

## **Executive Summary**

HIV has become one of the largest public health problems, especially in developing countries, and women are particularly vulnerable to infection. A Joint United Nations Programme on HIV/AIDS (UNAIDS) report indicates Sub-Saharan Africa accounts for 67% of the 33 million people living with HIV globally in 2007. In Southern Africa, the prevalence of HIV is between 15% and 28% of the adult population, or otherwise stated, around 22 million. Sixty percent of these adults are women. Among young people between the ages of 15 and 24, HIV prevalence tends to be notably higher among women than among men. The number of children younger than 15 living with HIV is estimated at 2.0 million, 90% of which live in Sub-Saharan Africa.

The countries with the highest HIV prevalence in the world can be found in Southern Africa, including Swaziland, Lesotho, Botswana, South Africa, Namibia, Malawi, Zambia and Zimbabwe. Cases of marginalization and violations of reproductive freedom of women living with HIV have been documented in several of these countries, including Namibia, Lesotho, South Africa, Zimbabwe, and Zambia. For example, health professionals have been reported to often pressurise HIV-positive women to accept contraception before being allowed to access treatment. In Namibia, 2 of 10 potential cases of forced sterilisation have been filed before the High Court by HIV positive women, while more than 40 such cases have been documented.

This study seeks to provide an overview of the evolution of reproductive health rights, to outline the obligations of States under international law, and to link women's reproductive health rights to HIV. It highlights a number of pertinent issues such as pregnancy and discrimination, control over fertility, family planning and access to contraceptive services, access to safe, legal abortion, HIV testing during pregnancy, and coerced or forced sterilisation. It also provides recommendations for international organisations and states.

## **Methodology**

The focus of the study is on Southern Africa. While throughout the study, examples gleaned through desk research are cited from various Southern African countries, Malawi and Botswana were chosen for field visits based on their high prevalence rates, and, in order to verify and complement the available literature generally in the region, on the reproductive health rights of women living with HIV.

The study was undertaken through internet-based desk research and literature review, complemented by field research in Botswana and Malawi. A total of 43 in-depth

individual interviews with women living with HIV and health care workers were conducted in these two countries in both urban and rural areas. In addition, a total of three focus group discussions with women living with HIV were held. Further, local NGOs in both Botswana and Malawi were also consulted for information.

### **Reproductive health rights in international human rights treaties, declarations, and guidelines**

Sexual and reproductive health rights are integral elements of the right to health, which is recognized and enshrined by United Nations (UN) human rights instruments such as the Universal Declaration on Human Rights (Universal Declaration), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) and the Convention on the Rights of the Child (CRC). It is also enshrined in the African regional and sub-regional human rights instruments including the African Charter on Human and Peoples' Rights.

The underlying concern of reproductive health is to empower women to control their own fertility and sexuality, as affirmed in the Cairo Programme and Beijing Declaration. The Cairo Programme affirms, and the Beijing Platform reaffirms, that 'the principle of informed free choice is essential to the long-term success of family planning programs [and that] any form of coercion has no part to play.' Reproductive rights have also been elaborated through general recommendations by both the ICESCR and CEDAW Committees, which monitor implementation of the treaties. In addition, three of the Millennium Development Goals (MDGs) relate to reproductive health: (1) MDG 3 to promote gender equality and empower women; (2) MDG 5 to improve maternal health; and (3) MDG 6 to combat HIV/AIDS, malaria, and other infectious diseases. In Africa, reproductive health rights are guaranteed in the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Women's Protocol) while in the Southern African region, the Southern African Development Community (SADC) Protocol on Gender and Development also guarantees women's reproductive health, and the SADC Health Protocol obligates state to take steps in order to deal with the HIV pandemic. Other human rights principles can be used to protect and promote women's reproductive health rights. These include the right to equality, non-discrimination, rights relating to individual freedom, self-determination and autonomy; rights regarding survival, liberty, dignity and security; rights regarding family and private life; rights to information and education; and the right to the highest attainable standard of health.

According to the International Guidelines on HIV/AIDS and Human Rights (International Guidelines), the protection of human rights is essential to safeguard human dignity in the context of HIV and to ensure an effective, rights-based response to HIV and AIDS. However, currently the reproductive health and rights of women in the context of HIV are inadequately addressed in policy at the international, regional, and national level of many states in Sub-Saharan Africa. In many settings, the negative views of health care providers toward the reproductive rights of HIV-positive women have been manifested in many forms.

In the absence of comprehensive guidelines on the reproductive health rights of women living with HIV, other existing guidelines and tools, although general, can be applicable. They include: recommendations from WHO on essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings and publications such as: *Guidance on ethics and equitable access to HIV treatment and care* by UNAIDS; *UNFPA/WHO Sexual and reproductive health of women living with HIV/AIDS: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings* by UNFPA/WHO; and *Reproductive choices and family planning for people living with HIV: Counselling tool* by WHO.

## **Issues related to women's reproductive health rights and HIV**

### **1. Pregnancy and discrimination**

The Universal Declaration proclaims that 'all human beings are born free and equal in dignity and rights.' Therefore, human rights belong to all without discrimination, a principle that has been enshrined in all major human rights treaties. After over two decades of the AIDS epidemic and 17 international AIDS conferences, stigma and discrimination based on misperceptions of HIV and AIDS is still pervasive, and even, at times, perpetuated by the very health care workers whom those vulnerable to infection, and those infected, turn to for help. Individuals, including health professionals, tend to stigmatize HIV-positive women, in particular, those seeking services related to reproductive decision-making. Negative experiences by women living with HIV include, but are not limited to: not receiving information relating to HIV and pregnancy; not receiving proper care when delivering because health care workers fear infection; and being blamed for serving as 'vectors' of the disease. In most instances, pregnancy for HIV-positive women is discouraged based on a number of reasons including: exposure

to re-infection for herself and her partner; exposure to infection for the baby; and weakened immune system.

## **2. The right to control fertility**

The right to control one's fertility means the right of a woman to reproductive autonomy. This encompasses the right to decide freely and responsibly if, when, and how often to reproduce. This right exists regardless of one's HIV status. Out of the estimated 200 million women who become pregnant each year, around 2.5 million are HIV-positive women. In the context of pregnancy, HIV creates a complicated intersection between HIV status and the childbearing desires of women. A considerable number of service providers are of the opinion that pregnancy ought to be prevented at all costs in HIV-infected women. As a result of such views, women are sometimes pressured to abort or subjected to permanent sterilization methods without their informed consent even though they desire children. Conversely, women who do not want children at all, or do not want to have more children beyond what they have, are unable to prevent pregnancy due to inadequate or inaccessible family planning services. Others are unable to safely terminate an existing pregnancy due to prohibitive abortion laws in their countries.

## **3. Family planning and access to contraceptive services**

The 2008 Millennium Development Goals Report indicates that in Sub-Saharan Africa, nearly one in four married women has an unmet need for family planning. The right to family planning is enshrined explicitly at the African regional level in the Women's Protocol. There is a direct relationship between a woman's fertility rights and the available contraceptive services. Studies show that access to family planning services for women and men living with HIV are not adequately addressed throughout the world and access to contraception is limited in many Sub-Saharan African settings. A study conducted in Botswana, for example, indicates that women's desire to control their fertility is hampered by the limitation of contraceptive options they have. HIV-positive women in Zambia reported difficulty in asking for, and accessing forms of, contraceptives other than condoms and one woman reported having been told that 'requesting contraceptives is a confirmation that you are not using condoms, exposing others to risk and exposing yourself to re-infection and more infections.' Family planning should be initiated during pre-test and post-test counselling and occur in follow-up information and counselling sessions as well as at regular intervals throughout care.

Family planning should include information on risks associated with pregnancy for HIV-positive women; on how to prevent unintended pregnancies through various contraceptive methods, and the risks and benefits associated with each method; and on how to prepare for a healthy pregnancy should that be the desired outcome of family planning. There is a need for explicit policies that recognize reproductive choice in HIV-infected individuals including improved access to contraception and other reproductive health care services.

#### **4. Unwanted pregnancy and access to legal abortion**

In Africa, the risk of dying following unsafe abortion is the highest worldwide, where 13% of maternal deaths are due to unsafe abortion. Many countries in Africa have restrictive abortion laws. In Malawi, abortion is permitted only to save a woman's life while in Botswana it is allowed in exceptional circumstances such as rape, when the health of the mother or the baby is at risk, defilement, and incest. Such laws violate women's right to reproductive autonomy and fail to take into account the reality of women's lives. Many pregnancies are unwanted, unplanned, and often unintended. Some, for example, are the result of sexual violence, including within marriage. In other cases, women cannot negotiate safe sex in their relationship and others cannot access contraception. Research indicates that HIV-positive women are terminating pregnancies in countries with numerous legal restrictions on abortion, and therefore are victims of unsafe abortions. As a result of restrictive laws, both UNAIDS and the International Community of Women Living with HIV/AIDS (ICW) have recommended that women living with HIV should have a right to choose to terminate a pregnancy upon learning of their HIV status and should be supported to do so without judgment. This move should however not be used to coerce or pressure HIV-positive women into having an abortion in cases where they desire to have children. The issue of unwanted pregnancy and access to abortion in relation to HIV is often ignored or avoided despite the fact that women living with HIV are frequently faced with unwanted pregnancies.

#### **5. HIV testing during pregnancy**

Literature on HIV, AIDS and women's rights usually focuses on prevention of perinatal transmission (PPT), often rendering women's rights secondary at best, if not non-existent. The goal of PPT of HIV has led to harsh policies in various settings, including HIV testing policies for pregnant women that threaten their autonomy, bodily integrity, and privacy. Even though many countries have chosen the route of provider-initiated testing and counseling (PITC), it is sometimes likely that a patient will not be made

aware of their right to refuse the test, nor be given the required information for informed consent. Women should make informed decisions before consenting to HIV testing. Testing and disclosure could have adverse consequences as laws criminalising the 'wilful' transmission of, or exposure to, HIV have been enacted and proposed in a number of states throughout Africa, including in Southern Africa.

## **6. Forced or coerced sterilisation**

HIV-positive pregnant women have recently been subjected to coerced or forced sterilisation. The ICW has documented 40 instances of coerced or forced sterilisation in Namibia whereby informed consent was not adequately obtained. Forced or coerced sterilisation adversely affects women's physical and mental health, and infringes upon the right of women to control their fertility and to decide on the number and spacing of their children. According to the International Federation of Gynecology and Obstetrics (FIGO), no incentives should be given or coercion applied to promote or discourage any particular decision regarding sterilization.

## **Conclusion**

The spread of the HIV will be significantly impeded, if not halted entirely, in societies where human rights are respected, protected, and fulfilled. As highlighted above, stigma and discrimination, barriers to controlling one's fertility, unmet family planning needs and lack of access to contraceptive services, restrictive abortion laws, mandatory HIV testing, and coerced or forced sterilisation are all issues confronted by women living with HIV, which threaten their human rights.

## **Recommendations**

- All Southern African states should draft a comprehensive rights-based reproductive health policy for women living with HIV, which comprises contraception, including emergency contraception, accessibility and affordability of PPT measures; ongoing antiretroviral treatment (ART) to ensure parents' survival; and measures to help women deal with unwanted pregnancies including safe, legal abortion.
- HIV-positive women should be included in policy-making, implementation, and oversight concerning reproductive health care.
- Safe termination of pregnancy must be available and accessible, to the full extent allowed by the law, to women living with HIV/AIDS who do not want to carry a pregnancy to term.

- Legislative reform should be undertaken, where necessary, with respect to restrictive abortion laws in order to create an enabling environment for safe, legal abortions for women living with HIV.
- HIV testing guidelines should be developed in accordance with human rights principles of informed consent and confidentiality. Voluntary counselling and testing should be the recommended testing regime. Where provider initiated testing and counselling is adopted, it must not single out pregnant women and must be conducted under rigorous conditions of pre- and post-test counselling and the minimum information, as outlined by WHO, must be provided in order to ensure consent. Mechanisms for redress should be established if these conditions are not met.
- Human rights training must be provided, especially concerning the reproductive health rights of women living with HIV, to all health care professionals, especially those who are involved in family planning, obstetrics and gynecology, and PPT programmes.
- Civil society must be supported to monitor government policies and performance on sexual and reproductive health issues.
- Men's involvement and participation in sexual and reproductive health services should be promoted toward the following goals: fostering positive behaviour change towards HIV prevention, and reducing the risk of partner infection or re-infection; mitigating the potential negative consequences of disclosure of positive test results; reducing the risk of STIs; educating and empowering men and women with information about family planning to prevent unwanted pregnancies, and encouraging communication and equality in reproductive decision-making.
- Ministries of Health should establish national procedures for reporting reproductive health rights violations, including forced or coerced sterilization and discriminatory treatment.
- Family planning counselling should be integrated into all phases of HIV care and treatment, including pre-test and post-test counselling and follow-up care. It should include an individual needs assessment in order to provide the most appropriate information.
- Southern Africa states that have not yet done so should ratify the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa. These countries are Botswana, Madagascar, Mauritius, and Swaziland.
- States should include in their periodic reports to international treaty bodies, in particular, the CEDAW Committee, the ICESCR Committee, and the African

Commission on Human and Peoples' Rights, efforts taken to protect women's reproductive rights, including reproductive choice, and identify areas for improvement.

- International treaty bodies, in particular, the CEDAW Committee, the ICESCR Committee, and the African Commission on Human and Peoples' Rights, should continue to include recommendations on reproductive health rights in their concluding observations to states.
- Relevant UN agencies such as UNFPA, UNIFEM, and UNHCHR should provide technical assistance to states in promoting and protecting women's reproductive health rights, particularly with respect to women living with HIV.
- International donors must earmark funding for strengthening national programmes and services that support and protect women's reproductive health rights, particularly those that integrate HIV and reproductive health services.

## 1. Introduction

This study was undertaken as part of a commemorative initiative for the 60<sup>th</sup> anniversary of the Universal Declaration of Human Rights (Universal Declaration).<sup>1</sup> It aims to highlight women's health, specifically the reproductive health rights of women living with HIV, as one theme within the Universal Declaration which needs increased prioritisation on the international human rights agenda, and at the national level, if the ideals of the document, which laid the foundation for the development internationally accepted human rights standards, are to be realised. Over the years, the right to health, recognised and guaranteed in international human rights instruments, including the Universal Declaration, has evolved to include women's reproductive health rights. However, despite the development of human rights norms, these rights are often not protected in many instances and there are numerous challenges to their realisation. For example, stigma and discrimination, violations of reproductive choice, unmet family planning needs, restrictive abortion laws, mandatory HIV testing, and coerced or forced sterilisation are challenges to the realisation of women's reproductive health rights in Southern Africa.

Such challenges are compounded in the context of the HIV pandemic. For more than two decades, HIV has become one of the largest public health problems, especially in developing countries, and women are particularly vulnerable to infection. Recent data indicates that of the 33 million people living with HIV globally in 2007,<sup>2</sup> Sub-Saharan Africa accounts for 67% of all people living with HIV, of which nearly 60% are women.<sup>3</sup> In Southern Africa, the prevalence of HIV is situated between 15% and 28% of the adult population or, otherwise stated; around 22 million people living with HIV are in Southern Africa.<sup>4</sup> It continues to bear a disproportionate share of the global burden of HIV. Southern Africa accounted for 35% of HIV infections and 38% of AIDS-related deaths in 2007.<sup>5</sup> Women are disproportionately affected in comparison with men, with especially stark differences between the sexes in HIV prevalence among

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<sup>1</sup> Swiss Initiative to Commemorate the 60th Anniversary of the UDHR - Protecting Dignity: An Agenda for Human Rights. For more information on the Swiss Initiative visit <http://www.udhr60.ch>. For the undertaking of this study, the authors are grateful for the generous funding from the Government of Switzerland and for the support from the Geneva Institute for Human Rights and Humanitarian Law, charged with coordinating the Swiss Initiative.

<sup>2</sup> UNAIDS 'Report on the global AIDS epidemic' (2008) [http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008\\_Global\\_report.asp](http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp) (accessed 24 March 2009).

<sup>3</sup> As above, 32-33.

<sup>4</sup> As above, 39.

<sup>5</sup> As above, 35.

young people.<sup>6</sup> The number of children younger than 15 living with HIV is estimated at 2.0 million, of whom 90% live in Sub-Saharan Africa. Factors including gender inequality, lack of education, cultural attitudes to sex, poverty, and violence make women more vulnerable to infection.<sup>7</sup> Infant and child mortality has noticeably increased in many sub-Saharan countries due to HIV infection, both as a direct result of vertical transmission, which increases child morbidity, and as a consequence of AIDS-related illnesses.<sup>8</sup>

Cases of marginalization and violations of reproductive freedom of women living with HIV have been documented in several African countries.<sup>9</sup> A 2008 study in South Africa noted that health policies, such as a Patients' Rights Charter, intended to advance both health objectives and rights entitlements were limited in their implementation by the beliefs and practices of health care providers. The same study cited evidence of health professionals in Namibia and Lesotho pressurising HIV-positive women to accept contraception before being allowed to access treatment.<sup>10</sup> In Namibia, 2 of 10 potential cases of forced sterilisation have been filed before the High Court by HIV positive women.<sup>11</sup>

Against this background, gaps have been identified in realizing HIV-positive women's reproductive choices and rights, including: inadequate attention to the sexual and reproductive health needs and of women living with HIV; poor quality of family planning services for women living with HIV; denial of safe, legal abortion; and evidence of coerced or forced sterilization of women living with HIV.<sup>12</sup> While these are global problems, these identified gaps are strikingly prevalent in Southern Africa.

The study aims to elaborate on some of the most pertinent issues affecting the reproductive health of HIV-positive women in Southern Africa. Information from field

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<sup>6</sup> As above page 41.

<sup>7</sup> S Mehta 'The AIDS pandemic: A catalyst for women's rights' (2006) 94 *International Journal of Gynecology and Obstetrics* 317.

<sup>8</sup> Centre for Reproductive Rights Briefing Paper 'Pregnant women living with HIV/AIDS: Protecting human rights in programs to prevent mother-to-child transmission of HIV' (August 2005) [http://reproductiverights.org/sites/default/files/documents/pub\\_bp\\_HIV.pdf](http://reproductiverights.org/sites/default/files/documents/pub_bp_HIV.pdf) (accessed 30 February 2009).

<sup>9</sup> The Centre for Reproductive Law and Policy *Women of the world: Laws and policies affecting their reproductive lives: Anglophone Africa* (2001) 163.

<sup>10</sup> L London et al "Even if you're positive, you still have rights because you are a person": Human rights and the reproductive choice of HIV-positive persons' (2008) 8(1) *Developing World Bioethics* 11.

<sup>11</sup> ICW report.

<sup>12</sup> ATHENA network fact sheet: Bridging the gap: Mapping emerging trends and neglected issues at the intersection of sexual and reproductive health and rights and HIV (March 2009) available at [http://www.athenanetwork.org/docs/ATHENA\\_Fact\\_Sheet.pdf](http://www.athenanetwork.org/docs/ATHENA_Fact_Sheet.pdf) (accessed 15 April 2009).

research undertaken in Botswana and Malawi on HIV-positive women's reproductive health rights is provided to illustrate relevant issues in practice in high prevalence, low resource settings in Southern Africa. Following the introduction, part two provides an overview of the evolution of reproductive health rights within the international human rights framework and outlines the obligations of States under international law to promote, protect and fulfil these rights. International guidelines are also included in this section. Part three links women's reproductive health rights to HIV, and highlights a number of pertinent issues: pregnancy and discrimination; control over fertility; family planning and access to contraceptive services; access to safe, legal abortion; HIV testing during pregnancy; and coerced or forced sterilisation. Finally, following a conclusion, the study provides concrete recommendations for international organisations and states.

## 1.1 Methodology

The focus of the study is on Southern Africa, where HIV-prevalence is highest in the world. The primary mode of transmission is through heterosexual intercourse, where women are vulnerable due to high levels of inequality in patriarchal societies manifested through a variety of women's rights violations, and where, stigma and discrimination and violations of reproductive health rights, have been reported. While throughout the study, examples gleaned through desk research are cited from various Southern African countries, Malawi and Botswana were chosen for field visits based on their high prevalence rates, and, in order to verify and complement the available literature generally in the region, on the reproductive health rights of women living with HIV. Studies on reproductive rights and health have been undertaken, for example, in South Africa, Namibia, Zimbabwe, and Zambia.<sup>13</sup> Insight into the problems and challenges in other parts of Southern Africa were sought through the interviews and focus groups in Botswana and Malawi.

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<sup>13</sup>See for example, International Community of Women Living with HIV/AIDS 'Positive women: Voices and choices Zimbabwe report' 2002 available at [www.icw.org/icw/files/VoicesChoices.pdf](http://www.icw.org/icw/files/VoicesChoices.pdf) (accessed 20 March 2009); International Community of Women Living with HIV/AIDS 'The forced and coerced sterilisation of HIV positive women in Namibia 2009' available at <http://www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf> (accessed 03 April 2009); Southern Africa Litigation Centre 'Brief summary of sexual and reproductive health and rights concerns of women living with HIV in Zambia' 2009 (on file with authors); J Harries, D Cooper et al 'Policy maker and health care provider perspectives on reproductive decision-making amongst HIV-infected individuals in South Africa' (2007) 7 *BMC Public Health* 282; L London, PJ Orner et al 'Even if you're positive, you still have rights because you are a person': Human rights and the reproductive choice of HIV-positive persons' (2008) 8(1) *Developing World Bioethics* 11.

The study was undertaken through internet-based desk research, complemented with exploratory research in Botswana and Malawi, where in-depth individual interviews and focus group discussions were conducted.<sup>14</sup> Thirteen women living with HIV and five health care workers were interviewed in Lilongwe. Two focus group discussions, facilitated with the assistance of a translator, with ten participants per group were held in rural Malawi, approximately 100km east of Lilongwe, and two health care workers were interviewed in the same location. NGOs were also consulted for information.

In Botswana, 21 women living with HIV were interviewed in urban and rural areas. Four women were from the capital city, Gaborone; five were from a large town, Lobatse; eight women were from a village called Gabane; and four women were from another village, Kanye. In addition, one focus group discussion with 12 participants was held comprising of women living in both Gaborone and Gabane. Four local NGOs were also consulted. All participants in Malawi and Botswana were provided with a small stipend to reimburse for their transport and compensate for their time.

Ethics approval for the field research component was obtained from the University of Pretoria, Faculty of Law Ethics Committee.

## **1.2 Limitations of the study**

The researchers experienced limitations to their field research in Malawi and Botswana. It was difficult to interview health care workers as government protocols for permission to do so were cumbersome and prohibitive in the time frame of the study, and we did not receive responses to our requests for access to staff of the public hospitals. The health care workers who were willing to speak to us did so in a neutral location outside of their working hours. There is always the potential for desirability bias and where discriminatory attitudes held by health care workers were not revealed through the interviews, it does not necessary confirm the absence of such attitudes. With the knowledge that the researchers were advocates for human rights, it would be understandably difficult for health care workers to admit to violations of human rights during the interviews.

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<sup>14</sup> With research assistance from Davinia Gomez Sanchez. The authors are also grateful for the assistance of Hye-Young Lim during conceptualisation of the study, and for the support and expertise of Professor Frans Viljoen, Director, Centre for Human Rights, University of Pretoria. We also acknowledge Grace Sedio, Miriam Nyoni, and Joyce Kamwana from the International Community of Women Living HIV in Botswana and Malawi respectively, for their invaluable assistance with the field research.

In rural Malawi, the two focus group discussions were conducted with the assistance of an English interpreter, one per group, who was recruited from the participating network of positive network. Despite the assistance in translation, language was a significant barrier to the discussions, as the English language skills of the translators were not sufficient, particularly with respect to terminology relating to reproductive health and rights. Consequently, the conclusions drawn from the focus group discussions may not be completely reflective of the situation in that particular rural area and the results may have varied or proven more insightful if the discussion could have been conducted without the above-stated limitation. Also, the researchers were only in Malawi and Botswana for one week respectively which made it possible to visit the capital city and only one rural area, in the case of Malawi, and two rural areas in the case of Botswana. In each location, treatment was available and accessible as well as PPT services. Our conclusions, therefore, are based on enquiries with a limited geographical focus and may have varied if all regions of the countries were explored. Despite these limitations, the field research was intended to be exploratory in order to supplement the literature on sexual and reproductive health rights of HIV-positive in the region. It was meant to enable the researchers to confirm or disprove the hypotheses drawn from desk research. In this respect, it was sufficient.

### **1.3 Background to the epidemic in Botswana and Malawi**

Southern Africa is heavily affected by the HIV epidemic and the countries with the highest HIV prevalence in the world can be found in this region, including Swaziland, Lesotho, Botswana, South Africa, Namibia, Malawi, Zambia, and Zimbabwe. Botswana has the third highest prevalence rate in the world despite having the most successful ART roll-out program in Africa, and having been the first African country to provide free ART to its citizens.<sup>15</sup> In 2007, the estimated number of people living with HIV in Botswana was 300 000 (between 20 and 28% HIV prevalence).<sup>16</sup> In the same year, 113 000 people had advanced HIV infection and 81.2% of those were on treatment.<sup>17</sup> Approximately 95% of pregnant women living with HIV received ART in 2007.<sup>18</sup> In the same year, the percentage of infants born to HIV-positive mothers who were infected with HIV was 4.8 compared to 20.7 in 2003.<sup>19</sup> Despite this achievement in prevention

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<sup>15</sup> UNAIDS (n 2 above) 275.

<sup>16</sup> As above, 41.

<sup>17</sup> As above, 9.

<sup>18</sup> As above, 275.

<sup>19</sup> 2008 Progress Report of the National Response to the UNGASS Declaration of Commitment on HIV/AIDS p 9 [http://data.unaids.org/pub/Report/2008/botswana\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/botswana_2008_country_progress_report_en.pdf) (accessed 02 April 2009).

of perinatal transmission, the Committee on the Rights of the Child had the following to say in its concluding observations in 2003 on Botswana's initial report to the CRC:<sup>20</sup>

the Committee shares the serious concern of the State party at the still exceedingly high prevalence rate of HIV/AIDS, especially among women in the childbearing years compounded, in part, by inappropriate traditional practices, stigmatisation and lack of knowledge on prevention methods.

While one can assume six years on, the Committee would be pleased that Botswana continues to address, with certain notable success, the above-stated concern, the problems have yet to be eradicated where treatment interventions have been more successful than prevention efforts, where the virus remains stigmatized, and where violence against women persists and continues to fuel the higher prevalence rate among women than men.

One of the five key goals stated in Botswana's National Strategic Framework for the period 2003 - 2009 is the provision of 'a supportive, ethical, legal, and human rights based environment conforming to international standards'.<sup>21</sup> In order to meet this goal, women's reproductive health rights must be respected and protected, particularly given their intersection with numerous other human rights including equality and non-discrimination, liberty, dignity, and the highest attainable standard of health. Ideally, the next Strategic Framework should specify protection of women's reproductive health rights as a key goal, rather than leaving it to interpretation under a broad category of human rights and international standards.

Malawi is one of the countries most severely affected by the HIV epidemic in Southern Africa. The general prevalence among adults aged between 15 and 49 was estimated to be 13.5% in 2007.<sup>22</sup> In the same year, the prevalence among pregnant women aged between 15 and 24 was 12.3%.<sup>23</sup> Only 32% of pregnant women in need of ART receive the treatment.<sup>24</sup> In 2007, 26% of HIV-positive pregnant women and their infants were receiving a complete package of PPT services to reduce the risk of perinatal transmission.<sup>25</sup> Malawi has increased the number of people on antiretroviral

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<sup>20</sup> Committee on the Rights of the Child 'Concluding observations of the Committee on the Rights of the Child: Botswana' (2003) CRC/C/15/Add.242.

<sup>21</sup> National Strategic Framework for HIV/AIDS in AIDS and Human Rights Research Unit (2007) *Human rights protected? Nine Southern African reports on HIV, AIDS and the law* PULP: Pretoria 9.

<sup>22</sup> 'Malawi HIV/AIDS Monitoring & Evaluation Report' (2008) Follow-up to the UN Declaration of Commitment of HIV and AIDS, 15.

<sup>23</sup> As above, 15.

<sup>24</sup> UNAIDS (n 2 above) 277.

<sup>25</sup> Office of the President and Cabinet 'Malawi HIV and AIDS Monitoring and Evaluation Report 2007: Follow up to the UN Declaration of Commitment on HIV and AIDS' ix available at

treatment from approximately 70 000 in 2006 to 150 000 in 2008.<sup>26</sup> As in many Southern African countries, there is concern over the 'feminisation' of the HIV epidemic in Malawi. Gender inequality, manifested in the low socio-economic status of women, high levels of gender-based violence and the persistence of harmful cultural and religious practices fuels the spread of the virus and accounts for the higher prevalence rate in women.

## **2. Reproductive health rights in international human rights treaties, declarations, and guidelines**

### **2.1. Treaties and declarations**

The first notion of a right to health under international law is found in article 25 of the Universal Declaration, adopted by the UN General Assembly in 1948 which provides for this right in a broad sense, stating the following:

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

While the Universal Declaration is not a legally binding document, it laid a strong foundation for the development of a body of international human rights law enshrined in legally binding covenants and conventions, within which the right to health was included. In the UN system of human rights treaties, it is to be found in the International Covenant on Economic, Social and Cultural Rights (ICESCR),<sup>27</sup> the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW)<sup>28</sup> and the Convention on the Rights of the Child (CRC).<sup>29</sup> It is also enshrined in regional and sub-regional human rights instruments including the African Charter on Human and Peoples' Rights,<sup>30</sup> as well as in the Protocol the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Women's Protocol).<sup>31</sup>

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[http://data.unaids.org/pub/Report/2008/Malawi\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/Malawi_2008_country_progress_report_en.pdf) (accessed 09 March 2009).

<sup>26</sup> Malawi: success in reducing HIV rate (30 April, 2008) available at [http://www.aidsportal.org/News\\_Details.aspx?ID=7751](http://www.aidsportal.org/News_Details.aspx?ID=7751) (accessed 05 April 2009).

<sup>27</sup> Art 12.

<sup>28</sup> Art 12.

<sup>29</sup> Art 24.

<sup>30</sup> Art 16.

<sup>31</sup> Art 14.

With respect to the right to health, as with all rights, in accordance with international law, states have an obligation to respect, protect, and fulfil. In other words, not only must states refrain from violating the right to health, they must take positive action, including measures that prevent third parties from interfering with the right and they must take legislative, administrative, budgetary, judicial, promotional, and other measures toward the full realization of the right to health.<sup>32</sup>

Sexual and reproductive health rights are integral elements of the right to health. The turning point for the development of the concept of reproductive health from a rights perspective was at the United Nations Conference on Population and Development (ICPD)<sup>33</sup> and the Fourth World Conference on Women (Beijing Conference),<sup>34</sup> which were held in 1994 and 1995 respectively.<sup>35</sup> The ICPD adopted the Cairo Programme of Action (Cairo Programme) and the Beijing Conference adopted the Beijing Declaration and Platform of Action (Beijing Platform). According to the Cairo Programme and Beijing Platform, reproductive health 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. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant.<sup>36</sup>

Reproductive health is one specific aspect of the right to health, and while it applies to men and women, there are aspects of the right which affect women in particular. From this definition it is evident that the underlying concern of reproductive health is to empower women to control their own fertility and sexuality with maximum choice and minimum health problems with the assistance of adequate and comprehensive reproductive information and services.<sup>37</sup> Furthermore, both these consensus documents maintain that free choice is central to abortion and sterilisation cases. The Cairo Programme affirms, and the Beijing Platform reaffirms, that 'the principle of

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<sup>32</sup> CESCR General Recommendation 14 para 33.

<sup>33</sup> The conference took place on 5-13 September 1994 in Cairo.

<sup>34</sup> The conference took place on 4-15 September 1995 in Beijing.

<sup>35</sup> See also C Ngwenya 'An appraisal of abortion laws in southern Africa from a reproductive health rights perspective' (2004) 32(4) *Journal of Law, Medicine and Ethics* 708.

<sup>36</sup> Para 7.2 of Cairo Programme of Action and para 96 of the Beijing Platform.

<sup>37</sup> C Bateup 'Can reproductive rights be "human" rights? Some thoughts on the inclusion of women's rights in mainstream human rights discourse' (2000) 3 *Australian Journal of Human Rights* 3.

informed free choice is essential to the long-term success of family planning programs [and that] any form of coercion has no part to play'.<sup>38</sup>

The language used by the Cairo Programme and Beijing Platform in defining reproductive rights is taken from the United Nations Convention on the Elimination of all Forms of Discrimination against Women (CEDAW). Whereas the Cairo and Beijing Declarations do not have the force of law and promote guiding principles only, CEDAW is legally binding on State Parties. Article 16 of CEDAW provides that State Parties shall ensure on a basis of equality of men and women 'the same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.' CEDAW also provides that women in rural areas should have access to adequate health care facilities including information, counseling, and family planning services.<sup>39</sup> This provision is important because the rates of maternal mortality are higher in rural areas since family planning and maternal health services are not as available as in urban places.<sup>40</sup> Further, State parties are obligated to take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.<sup>41</sup> Cook and Haws reveal examples of requirements that inhibit equal access to family planning such as the ability of husbands and not wives to obtain contraceptives without spousal authorization in some countries.<sup>42</sup> In some countries, unmarried men, but not unmarried women, may obtain contraceptive services; while in others, availability of voluntary sterilisation by women is managed differently from men.<sup>43</sup>

In the UN treaties, such as in the ICESCR and CEDAW, reproductive rights have been elaborated through general recommendations by the respective committees which have been established to monitor implementation of the UN treaty bodies. The general recommendations are intended to elaborate on respective treaty provisions.

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<sup>38</sup> Beijing paras 106(g) and (h), 107(e).

<sup>39</sup> Art 14(b).

<sup>40</sup> R Cook & J Haws 'The United Nations Convention on the Rights of Women: Opportunities for family planning providers' (1986) 12 *International Family Planning Perspectives* 50.

<sup>41</sup> Art 12(1) and 12(2) which require States Parties to ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

<sup>42</sup> As above.

<sup>43</sup> As above. For example, the availability of voluntary sterilization may be contingent on the number of caesarean sections that a woman has undergone or it may depend on the application of requirement like the 'rule of 80' which permits a woman to be sterilized only when the number of her living children multiplied by her age exceeds 80.

For example, the CEDAW Committee's General Recommendation 19 on violence against women calls on States Parties

to ensure that measures are taken to prevent coercion in regard to fertility and reproduction and to ensure that women are not forced to seek unsafe medical procedures such as illegal abortion because of lack of appropriate services in regard to fertility control.<sup>44</sup>

The same recommendation also states that 'compulsory sterilisation or abortion adversely affects women's physical and mental health, and infringes the rights of women to choose the number and spacing of their children.'<sup>45</sup>

General Recommendation 21 on equality in marriage and family relations also provides further detail on the respective right as enshrined in CEDAW noting,<sup>46</sup>

The responsibilities that women have to bear and raise children affect their right of access to education, employment and other activities related to their personal development. They also impose inequitable burdens of work on women. The number and spacing of their children have a similar impact on women's lives and also affect their physical and mental health, as well as that of their children. For these reasons, women are entitled to decide on the number and spacing of their children.

It also confirms that decisions to have children or not must not be limited and must be informed through information about contraceptive measures and their use acquired through sex education and family planning services.<sup>47</sup>

In General Recommendation 24 on women and health, the CEDAW Committee identified critical elements of women's health.<sup>48</sup> State parties are required to address distinctive features of health and life for women in contrast with men, taking into account biological factors such as differing reproductive functions, socio economic factors, psychosocial factors, and health system factors.<sup>49</sup> This recommendation further obligates states to prioritize the prevention of unwanted pregnancy through family planning, and sex education, and that legislation criminalising abortion should be amended to remove punitive provisions imposed on women who undergo abortion.<sup>50</sup> State parties must also take steps to prevent unethical practices against women in health care services, such as non-consensual sterilisation, mandatory testing for

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<sup>44</sup> General Recommendation 19 para 24(m).

<sup>45</sup> As above, para 22.

<sup>46</sup> General Recommendation 21 para 21.

<sup>47</sup> Para 22.

<sup>48</sup> CEDAW General Recommendation 24 UN GAOR (1999) Doc No A/54/38/Rev.1.

<sup>49</sup> As above para 12.

<sup>50</sup> As above para 31(c).

sexually transmitted diseases, or mandatory pregnancy testing as a condition of employment, as they violate women's rights to informed consent and dignity.<sup>51</sup>

The Committee on Social, Economic and Cultural Rights elaborated on the link between the right to health and sexual and reproductive health rights in General Comment 14 on the right to the highest attainable standard of health. With respect to article 12(1) of the ICESCR, concerning the definition of the right to health, the Committee states that 'the right to health contains both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom.'<sup>52</sup> Moreover, the Committee interprets the right to health, as defined in article 12(1), as 'an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as...access to health-related education and information, including on sexual and reproductive health'.<sup>53</sup> The comment further notes that article 12(2)(a) of the ICESCR may be understood as requiring measures to improve child and maternal health, sexual and reproductive health services including access to family planning, pre and post natal care and access to information as well as to resources necessary to act on that information.<sup>54</sup> The Committee recognises the unique requirements for realising the right to health for women, which includes attention to reproductive health:

To eliminate discrimination against women, there is a need to develop and implement a comprehensive national strategy for promoting women's right to health throughout their life span. Such a strategy should include interventions aimed at the prevention and treatment of diseases affecting women, as well as policies to provide access to a full range of high quality and affordable health care, including sexual and reproductive services. A major goal should be reducing women's health risks, particularly lowering rates of maternal mortality and protecting women from domestic violence. The realization of women's right to health requires the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health. It is also important to undertake preventive, promotive and remedial action to shield women from the impact of harmful traditional cultural practices and norms that deny them their full reproductive rights.

Finally, reproductive, maternal (pre-natal as well as post-natal) and child health care and the provision of appropriate training for health personnel, including education on health and human rights are listed as core obligations of states.<sup>55</sup>

The United Nations Millennium Declaration commits the world's nations to eight major goals, known as the Millennium Development Goals (MDGs), to reduce extreme

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<sup>51</sup> As above para 22.

<sup>52</sup> Para 8.

<sup>53</sup> Para 11.

<sup>54</sup> Para 14.

<sup>55</sup> Para 44(a)(e).

poverty by 2015. Three of these relate to reproductive health: MDG 3 to promote gender equality and empower women; MDG 5 to improve maternal health; and MDG 6 to combat HIV/AIDS, malaria, and other infectious diseases.

In the African regional system, the right to health is provided for in the African Charter on Human and Peoples' Rights.<sup>56</sup> Reproductive health rights are explicitly provided for in the Women's Protocol. It is the first binding international human rights treaty to explicitly guarantee reproductive health rights including, for the first time in international human rights law, the obligation to permit abortion under qualified circumstances.<sup>57</sup> Protection from HIV infection is another innovative feature of the Protocol.<sup>58</sup> The Women's Protocol protects the reproductive rights of women in a significantly more detailed manner than CEDAW.<sup>59</sup>

Several articles of the Women's Protocol, such as those relating to equality, non-discrimination, dignity, and marriage, for example, can, and should be, interpreted to create a strong legal basis for the obligation of state parties in relation to reproductive health. However, article 14 explicitly codifies the specific right of reproductive choice. It provides that 'State parties shall ensure that the right to health of women, including sexual and reproductive health is respected and promoted.'<sup>60</sup> This includes *inter alia*: the right of women to control their fertility and to decide whether to have children, the number of children and their spacing, the right to choose any method of contraception, and the right to self-protection and to be protected against sexually transmitted infections, including HIV/AIDS.<sup>61</sup> States must take all appropriate measures to: provide adequate, affordable, and accessible health services to women especially those in rural areas and, establish and strengthen existing pre-natal, delivery and post-natal health and nutritional services for women during pregnancy and while they are breastfeeding. For women living with HIV this must be interpreted to include access to prevention of perinatal transmission of HIV (PPT)<sup>62</sup> services. Finally, article

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<sup>56</sup> Article 16.

<sup>57</sup> Art 14(2)(c) provides for the authorisation of medical abortion in cases of sexual assault, rape, incest, and where the continued pregnancy endangers the mental and physical health of the mother or the life of the mother or foetus.

<sup>58</sup> As above (1)(d).

<sup>59</sup> D Chirwa 'Reclaiming (womanity): The merits and demerits of the African Protocol on Women's Rights' (2006) *NILR* 84.

<sup>60</sup> Art 14(1) (a) and (b).

<sup>61</sup> As above.

<sup>62</sup> Prevention of perinatal transmission of HIV (PPT) is used in this study to replace the commonly used terms prevention of mother to child transmission (PMTCT) and was taken from M de Bruyn 'HIV/AIDS and reproductive health, sensitive and neglected issues: A review of the literature, recommendations for action' (2005). De Bruyn asserts that use of PMTCT or prevention of parent to child transmission (PPCT) can carry unintended connotations of

14 obliges state parties to 'protect the reproductive rights of women by authorising medical abortion in cases of sexual assault, rape, incest, and where the continued pregnancy endangers the mental and physical health of the mother or the life of the mother or the foetus.'<sup>63</sup> While this provision falls short of guaranteeing reproductive autonomy for women, it does go further than any other legally binding internationally human rights treaty. It also gives women living with HIV authority to advocate for legislative reform of prohibitive abortion laws given that continued pregnancy can be harmful to their health and life threatening.

At the sub-regional level in Southern Africa, the SADC Protocol on Gender and Development (SADC Protocol), adopted on 16 August 2008 by the SADC Heads of State and Governments, also guarantees women's reproductive health rights.<sup>64</sup> It calls upon all member states to develop and implement policies and programmes to address the mental, sexual, and reproductive needs of women and men and to take into account the unequal status of women when developing such programmes.<sup>65</sup> Also relevant in the sub-region is the SADC Health Protocol which entered into force in August 2004. It obligates states to take certain steps in order to deal effectively with the HIV pandemic.<sup>66</sup> States must harmonise policies aimed at prevention and control of HIV, and to develop approaches for the prevention and management of HIV/AIDS. State parties are also obligated to formulate policies, strategies, and programmes which will, among other things, reduce maternal mortality and empower men and women to have access to safe, effective, affordable, and acceptable methods of fertility.<sup>67</sup>

Along with the provisions in international human rights law specific to reproductive health rights, numerous other human rights principles, enshrined in the Universal Declaration and other defining human rights instruments, are applicable to the promotion and protection of HIV-positive women's reproductive health rights.

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'blaming' the mother, or parent, if the newborn infant is infected. PMTCT is retained if included in a quote.

<sup>63</sup> Art 14(2).

<sup>64</sup> Art 26. The SADCC was established in April 1980 by Governments of the nine Southern African countries of Angola, Botswana, Lesotho, Malawi, Mozambique, Swaziland, Tanzania, Zambia and Zimbabwe. It was formalized by means of a Memorandum of Understanding on the Institutions of the Southern African Development Co-Ordination Conference on the 20<sup>th</sup> July 1981. The Treaty was adopted on 17 August 1992 in Windhoek, Namibia. SADC currently has 15 member states which are: Angola, Botswana, DRC, Lesotho, Malawi, Mauritius, Madagascar, Mozambique, Namibia, Seychelles, South Africa, Swaziland, Tanzania, Zambia and Zimbabwe. For the text of the treaty see [www.sadc.int](http://www.sadc.int) (accessed 15 August 2008).

<sup>65</sup> As above, art 27.

<sup>66</sup> SADC Protocol on Health, art 10.

<sup>67</sup> As above, article 16(b) and (d).

These include, but are not limited to: the right to equality and to be free from all forms of discrimination; rights relating to individual freedom, self-determination and autonomy; rights regarding survival, liberty, dignity and security; rights regarding family and private life; rights to information and education; and the right to the highest attainable standard of health. Violations of women's reproductive health rights are cross-cutting and inhibit the enjoyment of numerous other rights.

## **2.2 International guidelines on the reproductive health rights of women living with HIV**

According to the International Guidelines on HIV/AIDS and Human Rights (International Guidelines),<sup>68</sup>

the protection of human rights is essential to safeguard human dignity in the context of HIV and to ensure an effective, rights-based response to HIV and AIDS. An effective response requires the implementation of all human rights, civil and political, economic, social and cultural, and fundamental freedoms of all people, in accordance with existing international human rights standards.

The reference to all human rights includes women's reproductive health rights. However, there is a need for explicit rights-based guidelines addressing reproductive health rights and HIV in order to enumerate the responsibility of states to protect these rights especially in the light of their vulnerability to abuse. Currently, the reproductive health and rights of women in the context of HIV are inadequately addressed in policy at the international, regional, and national level of many states in Sub-Saharan Africa. Health care providers in South Africa, for example, identified a lack of clear policy guidelines and training around contraceptive counselling for HIV-infected individuals as a shortcoming in current reproductive health care services.<sup>69</sup> Guidance is necessary, in particular, for health care workers who, 'act as "gatekeepers" who guide both patient understandings of specific reproductive health care issues as well as access to reproductive health interventions.'<sup>70</sup> Health care workers, especially in low-resource settings, are unlikely to be trained in the application of human rights principles in the context of their work and may therefore, have little regard for human dignity or reproductive choice as a component thereof. Whereas human nature often precedes the 'lofty' language of human rights, even those with an understanding of fundamental rights are still subject to discriminatory perceptions or value judgements on which their health care advice could be based.

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<sup>68</sup> International Guidelines para 8(a).

<sup>69</sup> J Harries et al 'Policy maker and health care provider perspectives on reproductive decision-making amongst HIV-infected individuals in South Africa' (2007) 7 BMC Public Health 282.

<sup>70</sup> London et al (n 10 above).

In many settings, the negative views of health care providers toward the reproductive rights of HIV-positive women have been manifested in many forms including: judgmental remarks; failure to keep HIV status confidential; delay or denial of care for HIV-positive women; or pressure on HIV-positive women to act against their fertility desires. As one study notes:<sup>71</sup>

Providers play a crucial role in determining access to, and quality of, reproductive health services and their influence is likely to be heightened in delivering services to HIV-infected women. The perception that HIV-infected women should not engage in sexual relationships or have children could compromise health care services and impinge on HIV-infected individuals' reproductive rights and choice. Furthermore, providers may promote specific services such as sterilization or abortion and compromise or limit women's reproductive choices.

Health care providers should be provided with explicit guidelines to support and enable them to respect the reproductive health rights of women living with HIV and reduce the potential for their personal biases and moral judgements to influence their service. These guidelines should be based on international human rights standards. The International Guidelines state:<sup>72</sup>

One essential lesson learned from the HIV epidemic is that universally recognised human rights standards should guide policy makers in formulating the direction and content of HIV-related policy and form an integral part of all aspects of national and local responses to HIV.

In the absence of comprehensive guidelines on the reproductive health rights of women living with HIV, other existing guidelines, although general, can be applicable. However, they are broad, and only exceptionally well trained health care providers will be able to interpret their relevance in caring for the reproductive health needs of women living with HIV. States must therefore refine existing guidelines and translate them into national guidelines, policies and laws which target the sexual and reproductive health of women living with HIV.

The following are examples of existing guidelines, with one or more provisions relevant to the reproductive rights of women living with HIV. The International Guidelines<sup>73</sup> recommend that:<sup>74</sup>

States should, in collaboration with and through the community, promote a supportive and enabling environment for women, children and other vulnerable groups by

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<sup>71</sup> As above (n 69), 283.

<sup>72</sup> Para 99.

<sup>73</sup> Joint United Nations Programme on HIV/AIDS (UNAIDS) and Office of the United Nation High Commissioner for Human Rights 'International Guidelines on HIV/AIDS and Human Rights' (2006). See also UNAIDS Consolidated Version HR/PUB/06/9.

<sup>74</sup> Guideline 8 para 60.

addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

An enabling environment for women must include measures to address the reproductive health of women living with HIV and therefore, this particular guideline must be interpreted accordingly by policy makers who are intended to rely on the Guidelines in their national responses to HIV.

Another example of guidelines that can be applied to respecting the reproductive health rights of women living with HIV are the UNAIDS *Guidance on ethics and equitable access to HIV treatment and care*.<sup>75</sup> This document refers to the training needs of health care providers stating that

[a]part from trained counselors, it is critical that all other health staff be trained in gender and HIV/AIDS issues, in provider-client interaction and counselling techniques in order to provide a confidential and non judgmental environment.<sup>76</sup>

The guideline further stresses the importance of integration of HIV services with reproductive health services.<sup>77</sup> However, this guideline falls short of providing any meaningful guide to health care providers in relation to reproductive needs of HIV-positive women.

Another recent recommendation that may have a bearing on the reproductive rights of HIV-positive women is the recommendations from WHO on 'Essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings'.<sup>78</sup> These Guidelines indicate that people living with HIV have not only 'similar family-planning needs as the general population, but also have unique needs'.<sup>79</sup> The Guidelines emphasize the need for counselling to avoid unintended pregnancies and make informed decisions on sexual and reproductive health choices including access to a broad range of contraceptives, including condoms.<sup>80</sup> Most importantly, the guidelines caution:

In delivering these services, it is critical not to coerce individuals. Stigma and discrimination often undermine the human rights of people living with HIV. Therefore, family planning counselling and services should never be imposed on people living with

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<sup>75</sup> UNAIDS 'Guidance on Ethics and Equitable Access to HIV Treatment and Care' 2004 [http://data.unaids.org/Publications/External-Documents/who\\_ethics-equity-hiv\\_en.pdf](http://data.unaids.org/Publications/External-Documents/who_ethics-equity-hiv_en.pdf) (accessed on 02/04/2009).

<sup>76</sup> As above sec 4.7.

<sup>77</sup> As above.

<sup>78</sup> WHO 'Essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings' (2008) available at [http://www.who.int/hiv/pub/prev\\_care/OMS\\_EPP\\_AFF\\_en.pdf](http://www.who.int/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf) (accessed 10 April 2009).

<sup>79</sup> As above sec 4.10.

<sup>80</sup> As above.

HIV. Rather, providers must safeguard the rights of people with HIV - women, in particular - to make informed choices about their sexual and reproductive lives.<sup>81</sup>

These guidelines should be popularised at the local level and included in training initiatives for health care providers.

The most relevant guidelines for programme planners and health care workers are those issued by UNFPA and WHO entitled *Sexual and reproductive health of women living with HIV/AIDS: guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings* (UNFPA/WHO Guidelines).<sup>82</sup> Compared with the guidelines referred to above, these guidelines are comprehensive and specific to sexual and reproductive health, covering concerns of HIV-positive women which are lacking in the previous guidelines mentioned above. Notably, they emphasise the necessity of making gender equality a central component in the response to HIV, as well as of integrating gender-sensitive interventions into sexual and reproductive health services.<sup>83</sup> In order to achieve this, 'health services need to acknowledge and address the gender-specific concerns and needs of women while seeking to transform gender roles and create more equitable relationships.'<sup>84</sup>

The UNFPA/WHO Guidelines include a number of concrete recommendations on a broad range of issues including: testing for HIV; violence against women; family planning services including counselling for women living with HIV who are planning a pregnancy and counselling during pregnancy, childbirth and postpartum; anti-retroviral treatment and pregnancy; and access to safe and legal abortion for women living with HIV/AIDS.

Another useful document is *Reproductive choices and family planning for people living with HIV: Counselling tool* published by WHO in 2006. While not guidelines, but a tool, it is presented in a simple, user-friendly manner and is designed to help health workers to counsel people living with HIV on their reproductive choices and family planning in order to make and carry out informed, healthy, and appropriate decisions about their sexual and reproductive lives. The tool covers issues such as

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<sup>81</sup> As above.

<sup>82</sup> WHO 'Guidelines on Care, Treatment and Support for Women Living with HIV/AIDS and their Children in Resource-constrained Settings' (2006) <http://www.who.int/hiv/pub/guidelines/rhr/en/index.html> (accessed 7 April 2009). In the introductory part the guidelines, it is stated that the guidelines '...primarily targets national-level programme planners and managers responsible for designing HIV programmes and comprehensive sexual and reproductive health services for women. It may also be a useful resource for health care workers involved in efforts to improve the sexual and reproductive health of women and to provide treatment and care for women living with HIV/AIDS.'

<sup>83</sup> As above, 15

<sup>84</sup> As above.

preventing pregnancy and infection, and considerations related to having a baby, outlining the risks for the baby, the mother, and the partner. It explains the different contraceptive methods and their effectiveness, as well as provides guidelines on the appropriateness of each, how to use them, recommendations and contraindications. For those especially, with no, or limited training in counselling on these issues, it is an empowering, and useful tool with which they should be required to familiarise themselves.

The effectiveness of guidelines depends not on the relevance of the content, but also on how effectively they are communicated to the targeted audience. The broad and vague nature of international guidelines on the reproductive rights of HIV-positive women and the implication thereof was aptly summarized by London and others, when they stated:<sup>85</sup>

Current reproductive health guidelines remain largely non-prescriptive on the advisability of pregnancy amongst HIV-positive couples, mainly relying on effective counselling to enable autonomous decision making by clients. Yet, health care provider values and attitudes may substantially impact on the effectiveness of non-prescriptive guidelines, particularly where social norms and stereotypes regarding childbearing are powerful, and where providers are subjected to dual loyalty pressures, with potentially adverse impacts on rights of service users.

The absence of clear guidelines for health care providers, coupled with their lack of knowledge of human rights principles is likely to leave HIV-positive women at the mercy of health care providers. As one author has commented, in the absence of clear guidelines, it is natural that health care providers would resort to develop their own guidelines.<sup>86</sup> To avoid a situation where HIV-positive women are not left at the hands of judgmental health care providers, there is a need to develop clear guidelines and standards that are developed or adapted for the context in which they are designed to be applied. Furthermore, health care providers need reliable and ongoing supervision to ensure that guidelines are adhered to and emerging problems are resolved promptly. Moreover, even where guidelines are clear, human rights awareness initiatives need be ongoing in order to eradicate health care providers' judgmental attitudes.

Along with the development of guidelines, in particular at the national level, to address the sexual and reproductive health rights of women living with HIV, mechanisms of accountability should be established. Often reference is made to patients' redress mechanisms in the event of health care providers failing to comply

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<sup>85</sup> As above (n 70).

<sup>86</sup> Harries (n 69 above) 286.

with existing codes of conduct regulating their practice. The WHO/UNAIDS guidelines on provider-initiated HIV testing, for example, state:

Health facilities should develop codes of conduct for health care providers and methods of redress for patients whose rights are infringed. Consideration should be given to the appointment of an independent ombudsman or patient advocate to whom breaches of HIV testing and counselling protocols and codes of conduct can be reported.<sup>87</sup>

While specific to HIV testing, the WHO/UNAIDS recommendation is generally applicable to a wide range of sexual and reproductive issues. The importance of developing guidelines and mechanisms for redress has also been articulated by the CEDAW Committee in its findings regarding an individual communication against Hungary.<sup>88</sup>

The case was brought before the Committee by Ms A S, a Hungarian woman who visited a hospital for delivery, and underwent sterilisation without her consent. She was assisted by the European Roma Rights Center (ERRC) and the Legal Defence Bureau for National and Ethnic Minorities (NEKI), who jointly filed a complaint. The hospital claimed to have received the woman's signed consent, but it was never explained to the woman that she was to be sterilised. The hospital submitted as a defence that Hungary does not have guidelines on family planning and procedures for obtaining consent for sterilisation purposes. The CEDAW Committee criticized the Hungarian government for not having family planning policies, and ordered Hungary to take measures to ensure that the relevant provisions of CEDAW and the pertinent paragraphs of the Committee's General Recommendations 19, 21 and 24 in relation to women's reproductive health and rights are known and adhered to by all relevant personnel in public and private health centres, including hospitals and clinics.<sup>89</sup>

There are a number of issues that arise with respect to the development of guidelines on the reproductive rights of HIV-positive women. Experience has shown that lack of clear guidelines on reproductive rights in the context of HIV has left women at the mercy of health care providers who, in many instances have been judgmental and unhelpful. While suggesting for development of separate guidelines, it is important to note that they should not be seen as a replacement for human rights principles enshrined in human rights instruments.

Guidelines for health care providers in relation to reproductive needs of HIV-positive women should address a number of issues. In this regard, the guidelines should enable

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<sup>87</sup> WHO/UNAIDS 'Guidance on provider-initiated HIV testing and counselling in health facilities (2007) section 5.2.1 available at [http://wholibdoc.who.int/publications/2007/9789241595568\\_eng.pdf](http://wholibdoc.who.int/publications/2007/9789241595568_eng.pdf) (accessed 17 March 2009).

<sup>88</sup> Committee on the Elimination of Discrimination against Women Thirty-sixth session Communication No. 4/2004 (7-25 August 2006).

<sup>89</sup> As above, para 11.5.

health care providers to advise HIV-positive women to help them to: weigh up the risks and advantages of pregnancy; make choices about contraception; make choices about preventing future HIV infection, including condom use; make informed decisions about the care and feeding of the infant; make decisions about future fertility; and choose behaviours, which reduce the risk of contracting or spreading HIV. Guidelines for health care providers should put special emphasis on the human rights of HIV-positive women.

While, as stated, guidelines to enable HIV-positive women to exercise their reproductive health rights are important, there are also limitations to their role in addressing the myriad of challenges towards realising their rights if the law on issues affecting HIV-positive women in reproductive decision-making remains defective. For example, WHO and the International Guidelines support the right of positive women to have access to safe abortion where allowed by law.<sup>90</sup> Though this guideline advises health care providers to consider abortion as an option when counselling HIV-positive women, the qualification 'where allowed by law,' simply means that it does not pertain to HIV-positive women in many countries. Experience has also shown that guidelines do not guarantee HIV-positive women protection of their reproductive rights as health care providers remain ignorant of human rights principles and consequently, fail to translate guidelines into action.<sup>91</sup>

### **3. Women's reproductive health rights and HIV**

While women living with HIV have the same rights concerning their reproductive health as other women, they also have needs and concerns that are unique and may be confronted with violations of their rights on the basis of their HIV status. For example, they must take measures to reduce the risk of HIV transmission to their infants should they choose to bear children, or should they be faced with an unplanned pregnancy. Consequently, they are vulnerable to violations of their rights to privacy and informed consent during HIV testing when seeking ante-natal care, if their status was not previously known. Subsequently, and often when seeking treatment from health care providers they are subject to stigma and discrimination, viewed as 'vectors of disease', and judged for not only having had unprotected sex and risking their partners to infection, but also for risking giving birth to an infected child. These and other issues

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<sup>90</sup> WHO 'Pregnancy and HIV/AIDS' (2000) <http://www.who.int/me-diacentre/factsheets/fs250/en/print.html> (accessed on 19/03/2009). See also International Guidelines (n 66 above).

<sup>91</sup> M de Bruyn 'Women, reproductive rights, and HIV/AIDS: issues on which research and interventions are still needed' (December 2006) 24(4) *Journal of Health, Population and Nutrition* 413, 414.

confronted by HIV-positive women with respect to their reproductive health rights will be elaborated below.

### 3.1 Pregnancy and discrimination

The Universal Declaration proclaims that ‘all human beings are born free and equal in dignity and rights.’<sup>92</sup> Human rights belong to all without discrimination, a principle that has been enshrined in all major human rights treaties. The right to health is to be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.<sup>93</sup> States that discriminate against HIV-women by failing to protect, promote, and fulfil their right to the highest attainable status of health, are doing so not only on the basis of sex, but also on the basis of ‘other status’ which, the Commission on Human Rights has determined to apply to health status including HIV.<sup>94</sup> It would also apply to pregnancy. The history of the HIV pandemic is clouded with fear and discrimination. Failure to understand the nature of HIV has resulted in misguided policies thereby creating a poor relationship between the public and people living with HIV.<sup>95</sup> For decades, people living with HIV have been subjected to discrimination and stigmatization based on an unfounded fear. Nevertheless, two decades of progress in the respective fields of medicine and human rights have informed the international community better about the nature of HIV. It has been acknowledged that ‘the full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV/AIDS pandemic.’<sup>96</sup>

After over two-decades of the AIDS epidemic and 17 international AIDS conferences, stigma, and discrimination based on misperceptions of HIV and AIDS is still pervasive, and even, at times, perpetuated by the very health care workers whom those vulnerable to infection, and those infected, turn to for help. A considerable number of health care practitioners lack sufficient knowledge on HIV and AIDS and as a result, ignorance about the virus generally, and about the rights of women living with HIV, in

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<sup>92</sup> Art 1 United Nations Universal Declaration on Human Rights General Assembly Resolution 217 A (III) 10 December 1948.

<sup>93</sup> Art 2 ICESCR.

<sup>94</sup> Office of the United Nations High Commissioner for Human Rights, the Protection of Human Rights in the Context of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) (2003) available at [www.ap.ohchr.org/documents/E/CHR/resolutions/E-CN\\_4-RES-2003-47.doc](http://www.ap.ohchr.org/documents/E/CHR/resolutions/E-CN_4-RES-2003-47.doc) (accessed 15 April 2009).

<sup>95</sup> Unpublished: VA Balogun ‘The rights of HIV sero-positive Nigerian women to found a family: a sexual and reproductive rights discourse’ unpublished LLM thesis, University of the Free State, 2008 8.

<sup>96</sup> Resolution adopted by the General Assembly 60/262 Political Declaration on HIV/AIDS (2006).

particular, results in discrimination and stigmatization in health care settings, including obstetrical and gynecological care.<sup>97</sup> However, states have an obligation to ensure that health facilities, goods and services, including the underlying determinants of health, are accessible to all, especially the most vulnerable or marginalized sections of the population, without discrimination.<sup>98</sup>

According to Paul Hunt, the former UN Special Rapporteur on the Highest Attainable Standard of Health:<sup>99</sup>

The links between stigma, discrimination and the enjoyment of the highest attainable standard of health are complex and multifaceted. Together, discrimination and stigma amount to a failure to respect human dignity and equality by devaluing those affected, often adding to the inequalities already experienced by vulnerable and marginalized groups. This increases vulnerability to ill health and hampers effective health interventions. The impact is compounded when an individual suffers double or multiple discrimination on the basis of, for example, gender, race, poverty and health status.

Women living with HIV are often victims of discrimination on the basis of an intersection of all the above factors. Stigma and discrimination are amongst the main obstacles in HIV prevention. Individuals, including health professionals, tend to stigmatize HIV-positive women, in particular, those seeking services related to reproductive decision making. A study in Zimbabwe, for example, revealed negative experiences by HIV-positive women when seeking reproductive health services.<sup>100</sup> Some of the participants in the study admitted to non-disclosure of their HIV status to health workers in order to avoid discrimination.<sup>101</sup> One participant had not received proper care when delivering her child because the health care workers feared HIV infection.<sup>102</sup> Others reported being scolded by health workers for getting pregnant.<sup>103</sup> According to another report, a woman in Namibia was ignored by health care workers when seeking information on HIV and pregnancy and was told 'you are HIV-positive and you are pregnant, your baby already die [sic]'.<sup>104</sup> In an environment where HIV-based stigma is manifested,

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<sup>97</sup> As above, 7.

<sup>98</sup> CESCR General Comment No 14 para 12(b).

<sup>99</sup> Report of the Special Rapporteur, Paul Hunt, on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health UNDOC E/CN.4/2003/58

<sup>100</sup> Feldman R & C Maposhere 'Safer sex and reproductive choice: Findings from "Positive women: Voices and choices" in Zimbabwe' (2003) 11(22) *Reproductive Health Matters* 162.

<sup>101</sup> As above, 168.

<sup>102</sup> As above.

<sup>103</sup> As above.

<sup>104</sup> ICW 'The forced and coerced sterilisation of HIV positive women in Namibia' March 2009 available at <http://www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf> (accessed 03 April 2009).

HIV-positive women can be deterred from seeking services and consequently, endanger their health, and if pregnant, the health of their unborn child.

Commenting on discrimination in the context of HIV, one author stated that

[t]o be able to blame others is psychologically reassuring as it divides the society into 'us' and 'them'. 'Others' are guilty as a result of their behaviour. They are guilty not only of getting themselves ill, but also of infecting 'innocents'.<sup>105</sup>

Women are often blamed for the spread of HIV. One HIV-positive woman interviewed in Gaborone overheard a health care worker, in reference to HIV-positive women, saying 'these people make me sick. I am tired of them, why do they go on and sleep with men when condoms are everywhere. All they want to do is to infect us and their partners.' Women are blamed for being 'vectors of the disease', particularly through perinatal transmission. These sentiments regarding discrimination by health care workers were supported by the findings from the UN Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa.<sup>106</sup> The 2004 report states that a major challenge to ensuring access to care and treatment is stigma and discrimination based on societal perceptions that women are responsible for the disease.<sup>107</sup>

Based on the interviews and evidence from the media, the general feeling of women in Botswana is that they have been made to believe that women living with HIV should not be pregnant. Pregnancy is discouraged based on a number of reasons including: exposure to re-infection for herself and her partner; exposure to infection for the baby; weakened immune system; risk of death and child abandonment based on a reported old saying in Botswana, 'test today and die tomorrow.' Two health care workers interviewed in a peri-urban area of Botswana stated their personal belief that HIV-positive women should not have children, especially when they know their HIV status. Reasons cited for their belief were the danger of infecting partners and the baby, and that PMTCT should not be repeated, implying it is a waste of resources. They said that this is what the Ministry of Health and the media are preaching and that they are 'just agents'. One of the employees of a human rights NGO indicated that accessing PMTCT itself is a problem in cases where the pregnancy is for the second time. It was reported that health care workers are more understanding and willing to assist those women who did not know their status before they got pregnant. One

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<sup>105</sup> DS Mfecane 'Stigma, discrimination and the implication for people living with HIV/AIDS in South Africa' (November 2004) 1(3) *Journal des Aspects Sociaux du VIH/SIDA* 157,159.

<sup>106</sup> 'Facing the future together: Report of the United Nations Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa' 2004 <http://womenandaids.unaids.org/regional/docs/Report%20of%20SG%27s%20Task%20Force.pdf> (accessed 13 April 2009).

<sup>107</sup> As above 43.

woman reported being asked by a health care provider: 'Why are you pregnant again, you knew your HIV status yet you went on and indulged in sex, you are wasting the government's resources.' Fifteen out of 21 women also viewed PMTCT to be for women who are pregnant for the first time and as a result it should not be repeated.

In Malawi, however, no instances of stigma or discrimination in the health care system were reported to the researchers. All 13 of the women interviewed in Lilongwe were satisfied with their treatment in the public health care system as were the twenty women who participated in focus group discussions in the rural area. Possible explanations for this could be improved knowledge and understanding of HIV based on successful information campaigns and training programmes, including in the public health care system. Given our limitations noted above however, the reports from our small sample of women do imply that discrimination and stigma does not exist. The Medical Coordinator of *Medecins sans Frontiers* (MSF) - Belgium, Malawi Mission in Thyolo District, Southern Malawi confirmed by email, when queried about the apparent absence of discrimination in the public health care system, that in fact, it was not surprising that our findings revealed such. According to him, the nature of Malawi is not the 'activist kind' so it would be difficult to find reports of discrimination. Also, because MSF, founded in human rights principles, provides all the services, including training, in the District within which it is based, there are no accounts of discrimination there.<sup>108</sup>

Women suffer discrimination in many settings, including outside the health care system. A positive woman interviewed in Gaborone was released publicly before her self-founded support group from her duties as a peer support counsellor because she was pregnant. She was told that as a role model, she was not allowed to be pregnant and that she should stop her activities in the support group because she was not practicing safe sex.

Discrimination against HIV-positive women persists despite international human rights obligations to prohibit discrimination against women in every area. Violations of HIV-positive women's reproductive health rights which are discriminatory based on their HIV-status, have the effect of impairing and nullifying the recognition, enjoyment and exercise of their rights as envisaged by CEDAW and the African Women's Protocol. Stigmatising women with HIV is also a violation of their right to dignity. A South African Constitutional Court judge confirmed the link between stigma and

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<sup>108</sup> Email correspondence 27 April 2009 between Karen Stefiszyn and Dr Moses Massaquoi, Medical Coordinator MSF Belgium.

violations of the right to dignity when he stated: 'In view of the prevailing prejudice against HIV-positive people, any discrimination against them can ...be interpreted as a fresh instance of stigmatisation, and I consider this to be an assault on their dignity.'<sup>109</sup>

In some countries, discriminatory policies against HIV-positive women have been enacted which make the nature of discrimination HIV-positive women face more noticeable. In Bolivia, for example, it is a crime for a mother to infect her child with HIV through breastfeeding.<sup>110</sup> Ghana has severely curtailed access to breast milk substitutes for HIV-positive women by banning the sale, advertising or promotion of infant formula in public health facilities.<sup>111</sup> The Supreme Court of India on its part held in one case that HIV-positive individuals are under obligation not to marry.<sup>112</sup> Law makers of one Chinese province similarly made it a crime to marry anyone living with HIV.<sup>113</sup>

PTT programmes can be stigmatising in themselves, especially where they inadvertently disclose a woman's HIV status.<sup>114</sup> A study in Malawi noted the following potential initiators of HIV-related stigma for women enrolled in PMTCT programmes: routine HIV testing, six months exclusive breastfeeding, especially in societies where one would normally continue breastfeeding past six months; incentives, such as food supplements; home visits by PMTCT staff with whom the community may be able to identify as such; the location of the PMTCT programme if it is situated away from other health services; and PMTCT terminology which carries the implication of responsibility for transmission of the virus.<sup>115</sup> Health care providers should be sensitive to these initiators of stigma and undertake measures to carry out the required treatment and support with respect for the right to privacy and non-discrimination. Government PMTCT programmes should address these challenges during scale-up of treatment.

### **3.2 The right to control fertility**

The right to control one's fertility means the right of a woman to reproductive autonomy, including her right to decide freely and responsibly if, when, and how often to

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<sup>109</sup> *Hoffman v South African Airways* 2001 1 S.A 1 (CC) para 28.

<sup>110</sup> Center for Reproductive Rights Briefing Paper 'HIV/AIDS: Reproductive Rights on the Line (June 2002) 3.

<sup>111</sup> As above.

<sup>112</sup> As above.

<sup>113</sup> The provincial regulations also suggest that pregnant HIV-positive women should be persuaded to have an abortion. See Center for Reproductive Rights (note 25 above).

<sup>114</sup> See generally V Thorsen et al 'Potential indicators of HIV-related stigmatization: ethical and programmatic challenges for PMTCT programs' (2008) 8(1) *Developing World Bioethics* 43.

<sup>115</sup> As above.

reproduce.<sup>116</sup> Violations of reproductive autonomy negatively affect women's empowerment, of which being able to make informed decisions is an integral component. There are numerous impediments in Southern African countries however, to the realisation of this right. Social norms and cultural values can place significant pressure on women to bear at least one, although usually more, child and, in fact, their value to family and society can be determined by doing so. Many women desire children for a variety of other personal reasons and cannot imagine a life where such a desire is left unfulfilled. Other women do not want children at all or do not want to have more children beyond what they have already produced, yet they are unable to prevent unplanned pregnancies due to an inability to negotiate safe sex, or lack of access to adequate information provided by well-resourced family planning services. When confronted with an unplanned and unwanted pregnancy, many women are unable to safely terminate the pregnancy due to prohibitive abortion laws in their country.

The right to control one's fertility exists regardless of HIV status. An enabling environment for informed choice is required in order for women living with HIV to choose whether or not to have children, how many, and when. Out of the 200 million women who become pregnant each year, 2.5 million are HIV-positive women.<sup>117</sup> Studies have shown that more than 80% of all women living with HIV and their partners are in their reproductive age.<sup>118</sup> HIV gives rise to a number of complicated issues in different areas. In the context of pregnancy, it creates a complicated intersection between HIV status and childbearing desires of women. Despite increased availability of state-provided treatment, HIV-positive women's health can be threatened during pregnancy and labour, and there is a risk of babies becoming infected with HIV via perinatal transmission. This scenario creates a conflict for women living with HIV and impacts on their reproductive decision-making, whether it relates to a desire to reproduce or to inhibit reproduction.

The right of women to make decisions concerning fertility free of coercion is derived from autonomy, which implies that the notion of choice is imperative. However, HIV-positive women face strong pressure from community members and health care providers to give up the idea of having children, either because of the risk of perinatal HIV transmission or out of concern for the welfare of children raised by parents who

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<sup>116</sup> See also para 96 of the Beijing Platform, para 7.3 of the Cairo Programme and article 16(1)(e) of CEDAW.

<sup>117</sup> M de Bruyn 'Reproductive choice and women living with HIV/AIDS' December 2002. [http://www.ipas.org/Publications/asset\\_upload\\_file116\\_3009.pdf](http://www.ipas.org/Publications/asset_upload_file116_3009.pdf) (accessed 1 April 2009).

<sup>118</sup> T Delvaux and C Nostlinger 'Reproductive Choice for Women and Men Living with HIV: Contraception, Abortion and Fertility' (2007) 15(29) *Reproductive Health Matters* 46, 47.

may die prematurely of AIDS-related illnesses. A considerable number of service providers are of the opinion that pregnancy ought to be prevented at all costs in HIV-infected women.<sup>119</sup> A study undertaken in Cape Town, South Africa, to interrogate policy maker and health care provider perspectives on reproductive decision making amongst HIV-infected individuals uncovered diverse perspectives amongst the study participants. While almost all the health care providers interviewed for the study were aware of women's reproductive health rights, some public health care sector policy makers expressed concerns about the feasibility of reproductive choice in a context in which there were an increasing number of AIDS orphans and overstretched treatment services for HIV-infected people.<sup>120</sup> Women are sometimes pressured to abort or subjected to permanent sterilization methods without their informed consent which is a violation of their right to health, to control their fertility, to decide the number and spacing of children, and to found a family.<sup>121</sup>

Although not referring to HIV specifically, David Bentar argues that 'the problem with a right to reproductive freedom that is either very expansive or very strong is that exercising it can cause considerable harm – to those children who are thereby brought into existence.'<sup>122</sup> He suggests that 'procreation that stands a high chance of serious harm should be actively discouraged and sometimes even prevented.'<sup>123</sup>

In the absence of treatment, there is a 30% risk of HIV transmission to a child during the prepartum period, during labour and delivery, or post-partum through breastfeeding.<sup>124</sup> However, with the use of antiretroviral drugs, increasingly available in Sub-Saharan Africa, the risk has been reduced to 8 – 15%, as has been observed in public sector services in resource-limited settings in South Africa and elsewhere.<sup>125</sup> There are studies indicating that HIV-positive women still maintain their desire to have children despite their HIV status.<sup>126</sup> A study in South Africa found that personal desires

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<sup>119</sup> Center for Reproductive Rights and Federation of Women Lawyers Kenya 2008 Report 'At Risk: Rights Violations of HIV Positive Women in Kenya Health Facilities' 44. See also E Espelen (2007) *Women and Girls Living with HIV/AIDS: Overview and Annotated Bibliography*. This report prepared by Bridge indicates that in other cases, health care workers believe that women living with HIV should not have children and when they are pregnant they are put under pressure to have abortion or to be sterilized without being given information on alternative measures available at [www.ids.ac.uk/bridge](http://www.ids.ac.uk/bridge) accessed 9 September 2008.

<sup>120</sup> As above (n 69).

<sup>121</sup> As above.

<sup>122</sup> Benatar D 'Reproductive freedom and risk' (2006) 21 *Human Reproduction* 2491.

<sup>123</sup> As above.

<sup>124</sup> J McIntyre and P Brocklehurst 'HIV in pregnancy: A review' (Geneva: UNAIDS and WHO, 1999) WHO/CHS/RHR/99.15; UNAIDS/99.35E [http://data.unaids.org/Publications/IRC-pub01/jc151-hiv-in-pregnancy\\_en.pdf](http://data.unaids.org/Publications/IRC-pub01/jc151-hiv-in-pregnancy_en.pdf)

<sup>125</sup> London et al (n 10 above).

<sup>126</sup> Harries et al (n 69 above).

and family and societal expectations frequently outweighed the influence of HIV status in determining whether or not to have children.<sup>127</sup> The same study cited hope, happiness and a reason for living as factors influencing the desire for children amongst HIV-positive men and women.<sup>128</sup> However, concerns were noted by the study participants about childbearing, including the health of the infant, the risk of deteriorating health during pregnancy, fears of infecting an uninfected partner while trying to conceive, and the possibility of dying and condemning a child to orphanhood.<sup>129</sup> Along with the importance assigned to childbearing in Sub-Saharan Africa and the accompanying social pressure for women to produce offspring, as well as personal desires for motherhood, HIV-positive women are confronted with unique factors influencing their reproductive decisions.

Many HIV-positive women are willing to take the risks involved in pregnancy and childbearing and their right to make that decision must be respected and supported through information, treatment and care. Our findings, however, demonstrate that such respect and support is lacking in Malawi and Botswana and literature suggests the same in other Southern African countries.<sup>130</sup> For example, during a speech on World AIDS Day in 2006, the Botswana Minister of Health said the following:<sup>131</sup>

The only way to stop infections is to commit to zero HIV transmission lifestyle. This carries an obligation to surrendering oneself to a lifestyle that ensures no transmission of the virus. We see this particular challenge of zero transmission manifested more in the area of mother-to-child transmission of HIV. There is evidence that a number of pregnant mothers who are on ARV treatment, may have already known about their HIV positive status before pregnancy. This has generated considerable human rights-related controversy, regarding their right to choose to procreate despite their known HIV status. It is also Government's position that nobody has the right to knowingly transmit HIV or knowingly expose another person – partner, spouse or child - to possible HIV infection, while in pursuit of their own rights.

The Minister of Health, through the above comment, is discouraging HIV positive women from having children, a violation of their right to reproductive autonomy.

In Malawi, despite an obligation to provide non-directive counselling, health care workers, both in an urban and rural setting, stated, during interviews, that they advise women living HIV with one or more children already not to have children because of the risks to the women's health and the potential consequences for the

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<sup>127</sup> Cooper, D et al "Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa (2007) 65 *Social Science and Medicine* 274.

<sup>128</sup> As above 277.

<sup>129</sup> As above 279.

<sup>130</sup> London et al (n 10 above).

<sup>131</sup> Keynote address by the Minister of Health Honourable Professor Sheila Dinotshe Tlou at the World AIDS Day commemoration, Tsabong, Kgalagadi District 1 December 2006.

child, either of being infected with the virus, or being orphaned. If she does not have any children, she is advised to have one and then stop bearing children. As one health care worker explained, fulfilling cultural and social expectations are more important than avoiding any risks involved in childbearing. Such directive advice however, infringes on women's right to decide the number of children she will bear. If advised to discontinue having children, it is assumed to be in their best interest and in some cases, it may certainly be. However, what is the line between advice and coercion and would many women, especially given the unequal power relation between themselves and the health care provider, easily recognise coercion as such? While cases of coercion were not identified outright in Malawi, it is highly likely that women living with HIV have been coerced into making certain decisions under the guise of being informed.

Women living with HIV in urban and rural Malawi felt they were provided with appropriate information from health care workers before conception, during, and after pregnancy. They were informed of the risks pregnancy would pose to their health and that, if they should desire to be pregnant that they should first get healthy through good nutrition and accessing antiretroviral treatment. They were also informed of measures to prevent mother to child transmission. Their experiences concur with a UNAIDS/WHO review on HIV and pregnancy whereby components of counselling were identified that are necessary in order for women to be able to make a truly informed decision about their pregnancy.<sup>132</sup> They include, but are not limited to the following: the effect of pregnancy on HIV infection; the effect of HIV infection on pregnancy; the risk of transmission to the foetus during pregnancy, delivery, and breastfeeding; termination of pregnancy options; treatment options during pregnancy; interventions available to attempt to prevent mother-to-child transmission; infant feeding options; the need for follow-up of both mother and child; and future fertility and contraceptive options.<sup>133</sup> Despite the unanimous satisfaction by the women interviewed with the provision of information, at least two gaps were identified by the researchers in counselling: infant feeding options and treatment options during pregnancy.

Based on the information received from health care workers and HIV-positive women in Malawi, counselling on infant feeding options is inadequate. Rather than being informed of the risks and benefits of breastfeeding or formula feeding babies born to infected women, women are told to breastfeed exclusively for the first six months, after which time breastfeeding should be discontinued. The advice itself is in

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<sup>132</sup> London et al (n 10 above).

<sup>133</sup> As above.

line with international guidelines on HIV and infant feeding whereby exclusive breastfeeding followed by early weaning is recommended in settings where replacement feeding is not affordable, feasible, acceptable, sustainable, and safe,<sup>134</sup> as is the case with Malawi. However, the concern is with the disempowerment of women, as a result of directive counselling, to make an informed decision based on an understanding of the risks of benefits of the different feeding options.

Counselling is also often lacking with respect to PTT. From the information received, all women are automatically enrolled in PTT programs without being informed of the risks of the associated treatment and the right to refuse the treatment. Despite the best intentions of the health care system to prevent infection in the baby, the right to autonomy of the women is violated when their interests are rendered secondary to those of the foetus.

Control over one's body and fertility is more easily exercised in situations where one is informed and empowered to make relevant decisions, particularly where one is HIV-positive and having additional considerations. In Southern African countries, including those under focus, however, many women are subject to poverty and the resultant disempowerment and therefore, are susceptible to directive counselling or outright coercion where the power relations are unequal between themselves and those confronted within the health care system. Health care workers, untrained in human rights, will act on their own judgement which may be clouded in perceptions of holding a higher moral status. A human rights based approach to reproductive health and HIV, which would require legislation, policies, and guidelines based on internationally accepted human rights norms, to be enacted and implemented, is necessary to protect the rights of HIV-positive women to control their fertility.

### **3.3 Family planning and access to contraceptive services**

The 2008 Millennium Development Goals Report indicates that in Sub-Saharan Africa, nearly one in four married women has an unmet need for family planning based on the latest available data from 2005.<sup>135</sup> The right to choose whether, and when to have a child lies at the core of reproductive rights. As noted earlier in the study, the right to family planning is enshrined explicitly at the African regional level in the Women's

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<sup>134</sup> WHO/UNICEF/UNAIDS/UNFPA HIV and infant feeding: Guidelines for decision-makers (2003) Geneva available at [www.who.int/child-adolescent-health-new-publication/NUTRITION/HIV\\_IF\\_DM.pdf](http://www.who.int/child-adolescent-health-new-publication/NUTRITION/HIV_IF_DM.pdf)

<sup>135</sup> The Millennium Development Goals Report 2008 <http://www.un.org/millenniumgoals/pdf/The%20Millennium%20Development%20Goals%20Report%202008.pdf>

Protocol.<sup>136</sup> In order for HIV-positive women to make an informed decision regarding childbearing, regardless of their status, they must be informed and given access to safe, effective, affordable, and acceptable methods of family planning of their choice along with other reproductive health-care services, and the means to utilise such facilities.<sup>137</sup> There is a direct relationship between a woman's fertility rights and contraceptive services available. While WHO has confirmed the effectiveness and safety of the use of contraceptives by HIV-positive women, where access to safe and effective contraception is limited, the reproductive rights of HIV-positive women are curtailed. A study conducted in Botswana, for example, indicates that women's desire to control their fertility is hampered by the limitation of contraceptive options they have.<sup>138</sup> HIV-positive women in Zambia reported difficulty in asking for and accessing forms of contraceptives other than condoms and one woman reported having been told that 'requesting contraceptives is a confirmation that you are not using condoms, exposing others to risk and exposing yourself to re-infection and more infections'.<sup>139</sup> Even where contraceptives are available, women often do not possess adequate information to make the appropriate choice.<sup>140</sup>

Many advocates of people living with HIV and reproductive health rights posit that the reproductive rights of HIV-positive individuals can be better met by combining HIV-related services with family planning programmes.<sup>141</sup> This is confirmed by the UN Millennium Project Task Force on HIV/AIDS, Malaria, TB and Access to Essential Medicines, which stated:<sup>142</sup>

The great majority of HIV infections are transmitted sexually or during pregnancy, childbirth, or breastfeeding. The prevention, diagnosis, and treatment of sexually transmitted infections is a core reproductive health concern as well as an important HIV prevention intervention. Moreover, family planning programs have developed considerable knowledge and tools for conveying information and influencing sexual behaviour. Thus there are abundant reasons to foster strong links between reproductive health and HIV/AIDS programs and services.

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<sup>136</sup> Article 14 (1)(b) of the Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa (African Women's Protocol).

<sup>137</sup> Cairo Programme of Action (note 5 above) para 7.2.

<sup>138</sup> Ipas "There's nothing you could do if your rights were being violated"

Monitoring Millennium Development Goals in relation to HIV-positive women's rights' (July 2006) available at <http://www.icw.org/files/lpas%20MDG%20monitoring%20tool%20report%207-24-06.pdf> (accessed on 05/02/2009).

<sup>139</sup> Southern African Litigation Centre 'Brief summary of sexual and reproductive health and rights concerns of women living with HIV in Zambia' (March 2009).

<sup>140</sup> As above.

<sup>141</sup> Delvaux & Nostlinger (note 118 above), 46.

<sup>142</sup> UN Millennium *Project population, reproductive health and the Millennium Development Goals* (2005) available at [http://www.unmillenniumproject.org/documents/SRHbooklet\\_080105.pdf](http://www.unmillenniumproject.org/documents/SRHbooklet_080105.pdf) (accessed 20 February 2009).

Studies have shown that HIV-positive women have their own reasons to limit their fertility for reasons which include: not wanting to have HIV-infected children; having enough children already; wanting to avoid unprotected sex; and not having sufficient resources to care for a newborn child.<sup>143</sup> Therefore, integrated HIV-related services and family planning clinics would greatly enhance the ability of HIV-positive women to exercise their reproductive rights. Moreover, women seeking family planning services, naturally of reproductive age, and are possibly practicing unprotected sex, would benefit from integrated HIV programmes, such as voluntary counselling and testing, as well as education and behaviour changes initiatives.

Preventing unintended pregnancies for HIV-positive women is an important approach to preventing HIV transmission to infants.<sup>144</sup> According to the 2007 Government of Botswana Country Report to the United Nations General Assembly Special Session on HIV/AIDS,<sup>145</sup>

although there has been an impressive improvement in the uptake of PMTCT, the battle is not yet won in that a number of HIV positive pregnant women are repeat enrollers in PMTCT, presenting with second and third pregnancies. Data from surveys done in the country's second city of Francistown reveal that 65% of pregnancies among HIV positive and HIV negative women were unplanned, and 35% were unwanted.

One study found that reducing unintended pregnancies among HIV-positive women by 16% would be estimated to have the equivalent impact in averting HIV infection among infants as antiretroviral prophylaxis.<sup>146</sup> This supports the frustration expressed by the Country Director of the University of North Carolina Project (UNC) at Kumuzu Central Hospital in Lilongwe, Malawi. While not referring to family planning specifically, he expressed concern over the imbalance in government spending on treatment for HIV versus prevention. According to him, approximately 90% of resources to address HIV in Malawi are going to treatment for roughly 6-7% of the population given that of the 12-14% of the population infected with HIV only half of them will require treatment. Treatment offers an easily quantifiable indicator of progress in addressing the epidemic. Politicians want to be able to say how many people have been treated for

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<sup>143</sup> Ipas 'HIV/AIDS and reproductive health: Sensitive and neglected issues: A review of the literature recommendations for action' (January 2005) [http://www.ipas.org/Publications/asset\\_upload\\_file268\\_2956.pdf](http://www.ipas.org/Publications/asset_upload_file268_2956.pdf) (accessed on 11/03/2009) 20. See also London (n 7 above) 16.

<sup>144</sup> UNFPA and WHO 'Sexual and reproductive health of women living with HIV/AIDS Guidelines on Care, treatment and support for women living HIV/AIDS and their children in resource-constrained settings' (2006).

<sup>145</sup> Government of Botswana Country Report, United Nations General Assembly Special Session on HIV/AIDS, December 2007 available at [http://data.unaids.org/pub/Report/2008/botswana\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/botswana_2008_country_progress_report_en.pdf) (accessed 29 January 2009).

<sup>146</sup> As above.

HIV infection as a measure of success.<sup>147</sup> This is at the cost of neglecting prevention interventions, including family planning. Considering that averting unplanned pregnancies has numerous other benefits beyond HIV prevention, access to family planning services is limited in many settings in Sub-Saharan Africa.

Family planning should be initiated during pre-test and post-test counselling and occur in follow-up information and counselling sessions as well as at regular intervals throughout care.<sup>148</sup> It should include information on risks associated with pregnancy for HIV-positive women, how to prevent unintended pregnancies through various contraceptive methods, and the risks and benefits associated with each method, and how to prepare for a healthy pregnancy should that be the desired outcome of family planning. Information about emergency contraception should be available and it should be made widely accessible. Dual protection should also be promoted. This refers to simultaneous protection against both unplanned pregnancy and STIs and HIV and is achieved by using condoms alone or together with another effective method of contraception, including emergency contraception.<sup>149</sup> For women living with HIV, it is important to protect against unintended pregnancy, to prevent other STIs, and to prevent re-infection with other HIV strains.<sup>150</sup> However, difficulties women have in negotiating condom use with men are widely understood. During focus group discussions in rural Malawi, for example, it was revealed that it was a common sentiment among men that wearing a condom was like 'eating a sweet with the wrapper on' and the women participants experienced resistance to condom use by their partners. Amidst scaling up of male circumcision in many Sub-Saharan African countries, based on evidence that it can reduce the risk of transmission of HIV from females to males by 70%, it may become even more difficult for women to convince their male partners to wear condoms.

To address this challenge and others, increasing access to and quality of family planning services must be done together with ongoing initiatives toward gender equality, particularly through education, economic empowerment, and eradication of violence against women. Where gender inequality prevails, women are unable to decide freely on whether or not to bear children regardless of the availability and quality of services in place. A health care worker interviewed in Malawi illustrated this point by referring to a HIV-positive woman she had come into contact with during her seventh

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<sup>147</sup> Interview with Dr Francis Martinson, Country Director, UNC Project, Kumuzu Central Hospital, Lilongwe Malawi, 26 March 2009.

<sup>148</sup> WHO/UNFPA guidelines n 145 above.

<sup>149</sup> As above.

<sup>150</sup> As above.

unplanned pregnancy. Neither she, nor her seven children are alive today. Men must also become involved with women's reproductive health and receive family planning counselling together with their partner.

There is a need for explicit policies that recognize reproductive choice in HIV-infected individuals including improved access to contraception and other reproductive health care services. Notably, Malawi does have a national family planning policy and contraceptive guidelines which removed limitations, such as spousal consent and age, and promoted new approaches for accessing and expanding family planning services, including community based delivery of contraceptives to reach rural populations. Similar policies should be developed and implemented in Malawi, and other countries where they do not exist, to also address the family planning needs of HIV-positive women and to address health care provider biases which influence their service in family planning clinics. Religious views, for example, may influence them to discriminate or refuse to counsel unmarried adolescents or to promote abstinence only while withholding information about contraceptive options.<sup>151</sup>

However, even when policies are available, HIV-positive women may not be able to exercise their rights unless adequate training is given to health care providers to deal sensitively with the reproductive health care needs of HIV-infected individuals from both a psychosocial and biomedical perspective. Some women interviewed in Botswana said that the language used in guidelines on HIV encourage them to consult their doctors when they are planning to get pregnant. Yet it does not address the challenges they are facing. Most women are not in a position to negotiate safe sex with their partners due to cultural beliefs and issues of power, and the fact that even if a husband forces a woman to have sex with him, there is nothing that can be done since marital rape is not an offence in the country. Also, most pregnancies are not planned at all, so there is no way you can consult with your doctor. Moreover, even in cases where a woman is willing to consult, accessing the clinic requires financial resources for transportation, which they may not have, as most often these doctors are found in the large urban hospitals.

### **3.4 Unwanted pregnancy and access to legal abortion**

Restrictions on abortion have devastating effects on women's health and rights. In Africa, the risk of dying following unsafe abortion is the highest worldwide where 13%

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<sup>151</sup> Bharat S *et al* 'Meeting the sexual and reproductive health needs of people living with HIV: challenges for health care providers' (2007) 15 (29 supplement) *Reproductive Health Matters* 93.

of maternal deaths are due to unsafe abortion. A women's rights NGO in Malawi reported that unsafe abortions contribute to about 30 percent of Malawi's maternal mortality rates.<sup>152</sup> Many countries in Africa have restrictive abortion laws. Abortion in Botswana, for example, is governed by the 1991 Penal Code (Amendment) and is allowed in exceptional circumstances such as rape, when the health of the mother or the baby is at risk, defilement, and incest. Any woman who solicits abortion is liable to a term not exceeding three years whereas any person who administers abortion to a woman is liable for a term not exceeding seven years.<sup>153</sup> In Malawi, it is permitted only to save the woman's life. Any woman who solicits abortion in Malawi is liable to seven years imprisonment while any person who administers abortion is liable to fourteen years imprisonment.<sup>154</sup> Such laws violate women's rights to reproductive autonomy and fail to take into account the reality of women's lives.

According to Cook,<sup>155</sup>

the practical effect of moral or principle-based law on women's health and status has historically been discounted, since institutions of moral authority such as religious institutions, legislatures, academic institutions and professional associations have historically tended not to include women, and in many cases, have expressly excluded women. Accordingly, the law, as an instrument of the state, served purposes identified by men, and applied techniques that men considered appropriate but whose dysfunctions men did not experience or appreciate.

Prohibitive abortion laws only affect women's health; therefore, denial of abortion services also violates the right to equality and non-discrimination enshrined in all international and regional human rights treaties. This point was also emphasised by the CEDAW Committee, which noted that the denial of medical procedures that only women need amount to a form of discrimination against women.<sup>156</sup>

WHO defines unplanned pregnancy as a pregnancy that is not expected and unwanted pregnancy as a pregnancy that for a variety of often overlapping reasons is unexpected and undesired.<sup>157</sup> This definition indicates that a pregnant woman decides of her own free will that pregnancy is undesired. Considering that 38% of pregnancies

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<sup>152</sup> A list of critical issues to the 6<sup>th</sup> periodic report of Malawi on CEDAW. Identified by WLSA Malawi. Prepared and submitted by S White & T Kachika. January 26, 2009. Page 8.

<sup>153</sup> Penal code S 160(1) and S 161.

<sup>154</sup> Penal Code sec 150 and 149 respectively.

<sup>155</sup> RJ Cook RJ & BM Dickens 'Considerations for formulating reproductive health laws' (2000) World Health Organisation Occasional Paper 3.

<sup>156</sup> CEDAW General Recommendation 24, para 14.

<sup>157</sup> World Health Organisation, 2006. *Unsafe Abortion: The Preventable Pandemic*. Geneva: WHO.

are unplanned, impediments to reproductive choice must be considered.<sup>158</sup> Many pregnancies, for example, are the result of sexual violence, including within marriage, which in Malawi and Botswana can occur with impunity in the absence of legislation addressing marital rape. In many countries in Sub-Saharan Africa, children are having children upon being forced into marriage. Other unintended pregnancies result from ignorance as a result of denied sex education. Many women cannot negotiate safe sex in their relationship and others cannot access contraception in situations, for example, where it is only available in centres beyond the reach of rural women. Unplanned pregnancies amongst HIV-positive women can have serious negative health consequences if they are not receiving treatment and require it, for example, or not in an optimum state of health pre-conception.

Research indicates that HIV positive women are terminating pregnancies in countries with numerous legal restrictions on abortion.<sup>159</sup> Many of them are victims of unsafe abortion as such abortions are normally carried out by persons lacking the necessary skills and in circumstances that lack minimal medical standards. In Malawi, women have attempted to abort through the ingestion of herbs, bleach, gasoline, and gun powder, or by inserting sharp objects such as twigs and pouches filled with arsenic into the vagina.<sup>160</sup> Complications from unsafe abortion have been cited as one of the reproductive health problems facing the sub-region.<sup>161</sup> UNAIDS has since recommended that women living with HIV should have a right to choose to terminate a pregnancy upon learning of their HIV status and should be supported to do so without judgment.<sup>162</sup> Such a motion is also supported by the ICW.<sup>163</sup> Some legal experts believe that it is unnecessary to specifically mention HIV as one of the grounds to

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<sup>158</sup> A report by the Alan Guttmacher Institute entitled 'Sharing responsibility: women, society and abortion worldwide' indicates that of the estimated 210 million pregnancies that occur throughout the world each year, 38% are unplanned. In developing countries, of the 182 million pregnancies occurring each year, an estimated 36% are unplanned and 20% end in abortion. Available at [www.guttmacher.org/media/nr/abortww\\_nr.html](http://www.guttmacher.org/media/nr/abortww_nr.html) (accessed 19 February 2009)..

<sup>159</sup> See for example, M de Bruyn 2005 'HIV/AIDS and reproductive health, sensitive and neglected issues: A review of the literature and recommendations for action.' The same findings were made by WHO 'Women and HIV and mother-to-child transmission' Fact sheet 10. [http://www.who.int/health-service-delivery/HIV\\_aids/English/fact-sheet-10/index/html](http://www.who.int/health-service-delivery/HIV_aids/English/fact-sheet-10/index/html) (accessed 5 March 2009).

<sup>160</sup> P Semu-Banda 'Women's rights group sues government over abortion rights' Health Malawi Apr 29, 2009 available at [www.ipsnews.net/africa/nota.asp?idnews=46671](http://www.ipsnews.net/africa/nota.asp?idnews=46671) (accessed 29 April 2009).

<sup>161</sup> Sexual and Reproductive Health Strategy for the SADC Region 2006-2015, September 2006. The aim of the strategy is to provide a policy framework and guidelines to accelerate the attainment of healthy sexual and reproductive life for all SADC citizens.

<sup>162</sup> J Goodwin 'Recommendations on integrating human rights into HIV/AIDS responses in Asia-Pacific region' (2004) available at [www.un.or.th/ohchr/issues/hiv aids/EpertMeeting\\_2004/recommendations.Pdf](http://www.un.or.th/ohchr/issues/hiv aids/EpertMeeting_2004/recommendations.Pdf) (accessed 15 April 2009).

<sup>163</sup> ICW 'ICW vision paper 1, HIV positive young women' (2004) available at [www.icw.org/tiki-index.php?page](http://www.icw.org/tiki-index.php?page) (accessed 02 February 2009).

terminate a pregnancy because HIV status should entitle her to a legal abortion where abortion is permitted to protect a woman's health or life.<sup>164</sup> This move should however, not be used to coerce or pressure HIV positive women into having an abortion in cases they desire to have children. ICW has reported their members have felt that sometimes health-care workers present abortion as the only option for HIV-positive pregnant women and have felt coerced to have an abortion.<sup>165</sup> Others have been provided with abortions, where legal, such as in South Africa, for example, on the condition that they consent to sterilisation after the procedure.<sup>166</sup>

In 2003, WHO published *Safe abortion: Technical and policy guidance for health systems*.<sup>167</sup> While arguably of little relevance in countries where abortion is prohibited, they do offer sound guidance that could be applied in situations where abortion is allowed if the mother's health is at risk or her life or the life of the foetus is threatened, and where HIV is acceptable as permissible grounds for abortion under such qualifications, even if not explicitly provided for in law or policy. According to these Guidelines, the provision of information is an essential part of good quality abortion services and as a result, information given must be complete, accurate and easy to understand.<sup>168</sup> The Guidelines further provide that: if a woman opts for abortion, the health care worker should explain legal requirements for obtaining abortion, a woman should be given as much time as she needs to make a decision and the health worker should also provide information for women who decide to carry the pregnancy to term and/or consider adoption.<sup>169</sup> The Guidelines further note that it is essential for health professionals and others such as police, court officials as well as the public to have accurate information and to understand clearly what is allowed under the law in their country.<sup>170</sup> Women trying to resolve the problem of an unwanted pregnancy may often feel they are in a vulnerable position, therefore they should be given adequate information so that they can make a choice about having or not having abortion to the extent permitted by the law.<sup>171</sup> It is therefore recommended that health providers should also be aware of situations in which a woman may be coerced into

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<sup>164</sup> M de Bruyn (n 62 above), 43.

<sup>165</sup> ICW 'Addressing the needs of HIV-positive women for safe abortion care' (January 2008) available at [http://www.hst.org.za/uploads/files/icw\\_abortion.pdf](http://www.hst.org.za/uploads/files/icw_abortion.pdf) (accessed 04 April 2009).

<sup>166</sup> As above.

<sup>167</sup> WHO 'Safe abortion: Technical and policy guidance for health systems' (2003) available at [http://www.who.int/reproductive-health/publications/safe\\_abortion/safe\\_abortion.pdf](http://www.who.int/reproductive-health/publications/safe_abortion/safe_abortion.pdf) (accessed 04 April 2009).

<sup>168</sup> As above, 26.

<sup>169</sup> As above.

<sup>170</sup> As above 85.

<sup>171</sup> As above 65.

having an abortion against her will, based, for instance, on her health status such as being infected with HIV. In such cases, the provider should endeavour to ensure fully informed and free decision-making.<sup>172</sup> The guidelines apply to all women, and do not address specific concerns of women living with HIV. However, as HIV-positive women may have unique concerns regarding abortion, including their legal eligibility for accessing abortion based on their health status, and risks of the procedure to their health and life, specific guidelines on safe abortion should be drafted or the existing ones should be amended to include a section on access to safe abortion and HIV-positive women.

The central elements of a policy required to ensure access to safe abortion services should aim to: minimise the rate of unwanted pregnancy and thus the recourse to abortion by providing good quality family planning information and services, including emergency contraception; ensure that every woman legally eligible has access to safe abortion services; meet the particular needs of groups such as poor women, adolescents, refugees and displaced women HIV infected women, and survivors of rape.<sup>173</sup>

The issue of unwanted pregnancy and access to abortion in relation to HIV is often ignored or avoided despite the fact that women living with HIV are often faced with unwanted pregnancies.<sup>174</sup> The problem is exacerbated by the fact that abortion still remains a highly stigmatized issue. Though women living with HIV have the right to have children and must also have access to measures to prevent perinatal transmission of HIV, they must also have the right to prevent unwanted pregnancy.<sup>175</sup> This view is also supported by UNAIDS in its strategy which advocates for prevention of HIV among prospective parents, prevention of unwanted pregnancies, and PTT.<sup>176</sup>

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<sup>172</sup> As above.

<sup>173</sup> See page 87-89, guidelines.

<sup>174</sup> De Bruyn (n 62 above) 2.

<sup>175</sup> De Bruyn M et al (2000) "HIV/AIDS, pregnancy and abortion-related care: A preliminary inquiry, 2.

<sup>176</sup> UNAIDS 2002 Where prevention and care meet: voluntary counselling and testing, and preventing mother-to-child-transmission. Report on the Global HIV/AIDS Epidemic 2002 122-132 available at <http://www.unaids.org/barcelona/presskit/barcelona%20report/contents.html> (accessed 15 March 2009). Referred to by de Bruyn *et al* HIV/AIDS, Pregnancy and Abortion-Related Care. A Preliminary Inquiry. Ipas: Chapel Hill, 2002.

In order for women living with HIV to make an informed decision regarding termination of pregnancy,<sup>177</sup>

they need to know the risks of pregnancy to their own health, the risks of transmission of HIV to their infant and the effectiveness and the availability and cost of antiretroviral drugs for treating HIV infection and for preventing HIV infection among infants as well as the potential toxicity of such drugs. They also need to know the side effects and risks of the abortion procedures available. The woman should make the final decision to terminate a pregnancy.

Furthermore, aside from counselling for women confronted with an unwanted pregnancy and wanting to terminate it, health care providers should be able to provide further information about family planning methods, including emergency contraception, referrals to post-rape services, information and advice about sexual and reproductive health rights, and information about and referrals to HIV care, treatment and support services.<sup>178</sup> However, it would take an exceptional health care provider, trained and knowledgeable in international standards pertaining to women's reproductive health rights to provide such information comprehensively, in a non-judgemental, non-directive manner. With respect to the sensitive issue of abortion, health care providers are more likely to hold inflexible opinions deeply rooted in religion or personal notions of morality. Furthermore, the question arises of the relevance of such counselling in countries, such as Botswana and Malawi, where abortion is illegal unless a woman can successfully make an unprecedented<sup>179</sup> case that the pregnancy, given her HIV status, is a risk to her life. In countries with restrictive abortion laws, any counselling in line with the above-mentioned guidance is futile in the absence of an environment supportive of reproductive autonomy.

Amongst health care workers in Botswana and Malawi, with few exceptions, legalising abortion was unsupported. While some did concede a woman should have the right to choose, personal beliefs based on religion and morality, ultimately determined their position, taking precedence over a rights approach. One view was that legalising abortion is 'encouraging prostitution'. Other women and health care commented that abortion, if motivated by fears relating to HIV status, was unnecessary given the wide availability of treatment and the significant reduction in risk of HIV transmission to a child. Fears about the increased risks of abortion for HIV-positive

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<sup>177</sup> WHO/UNFPA 'Guidelines on Care, Treatment and Support for Women Living with HIV/AIDS and their Children in Resource-constrained Settings' (2006) <http://www.who.int/hiv/pub/guidelines/sexualreproductivehealth.pdf> (accessed 7 April 2009).

<sup>178</sup> ICW 'Addressing the needs of HIV-positive women for safe abortion care' (June 2008) available at [http://data.unaids.org/pub/Report/2008/botswana\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/botswana_2008_country_progress_report_en.pdf)

<sup>179</sup> According to our research and knowledge.

women, even in a clinical setting, were also expressed. None of the women living with HIV or the health care workers interviewed in Malawi believed that abortion should be mandatory for HIV-positive women.

### **3.5 HIV testing during pregnancy**

Although much has been written about HIV, AIDS and human rights in relation to women's vulnerability to the pandemic, the main focus has often been on PPT, often rendering women's rights secondary at best, if not non-existent. The goal of preventing perinatal transmission of HIV has led to harsh policies in various settings, including HIV testing policies for pregnant women that threaten their autonomy, bodily integrity and privacy. Furthermore, in violation of the right to the highest attainable standard of health, testing pregnant women for HIV is, at times, made a condition for accessing pregnancy related care and services, even if the condition is not explicit and policy dictates against it. Many countries, including Botswana and Malawi, have chosen the route of provider-initiated testing and counselling (PITC) in line with recent WHO/UNAIDS guidance on provider-initiated HIV testing and counselling in health facilities.<sup>180</sup> Given the endorsement of WHO and UNAIDS, it is perceived as an acceptable route towards testing scale-up and in line with human rights principles of liberty, and informed consent, given that, in principle, a patient can opt out of the test. However, in practice, there is a fine, often invisible line, between mandatory or PITC. While in principle, and if implemented in strict adherence with the guidelines, PITC can respect human rights, in practice, particularly in resource-strained settings, rights will be violated. In the absence of highly skilled health care providers, well trained in human rights principles, it is likely that a patient will not be made aware of their right to refuse the test, nor be given the required information for informed consent, which is still required under this testing regimen.

According to the WHO/UNAIDS Guidelines, referred to above, the health care provider should provide the patient with the following minimum information in order to obtain informed consent: the reasons why HIV testing and counselling are being recommended; the clinical and prevention benefits of testing and the potential risks, such as discrimination, abandonment, or violence; the services that are available in the case of either an HIV-negative or an HIV-positive test result, including whether the antiretroviral treatment is available; the fact that the test result will be treated

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<sup>180</sup> WHO/UNAIDS 'Guidance on provider-initiated HIV testing and counselling in health facilities' (2007) [http://whqlibdoc.who.int/publications/2007/9789241595568\\_eng.pdf](http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf) (accessed 2 April 2009).

confidentially and will not be shared with anyone other than health care providers directly involved in providing services to the patient; the fact that the patient has the right to decline the test and that testing will be performed unless the patient exercises that right; the fact that declining an HIV test will not affect the patient's access to services that do not depend on knowledge of HIV status; in the event of an HIV-positive test result, encouragement of disclosure to other persons who may be at risk of exposure to HIV; and an opportunity to ask the health care provider questions.<sup>181</sup>

Informed consent reflects the concept of autonomy and of decision making of the person requiring and requesting medical and/or surgical interventions. However, WHO noted that it has become conventional to express informed decision-making as informed consent which is an inaccurate and often dysfunctional expression.<sup>182</sup> As a result, it recommends that this concept should be replaced by informed decision-making or informed choice in order to emphasise the providers' duty to disclose information, rather than to obtain consent.<sup>183</sup> This view is also supported by Cook and Dickens who say that the use of the phrase 'informed consent' by different legal systems is flawed as its emphasis is on obtaining consent rather than disclosing relevant information.<sup>184</sup>

Some patient groups may be more susceptible to coercion and adverse outcomes, and in such cases additional measures to ensure informed consent are recommended. This would apply to pregnant women and includes, emphasis on the voluntary nature of the test and the patient's right to decline it; additional discussion of the risks and benefits of HIV testing and disclosure of status; and further information about available social support.<sup>185</sup> Finally, for pregnant woman, or women planning a pregnancy, there is additional information that is required to be provided prior to the test. The risks of transmitting HIV to the infant must be explained along with measures that can be taken to reduce mother-to-child transmission, including antiretroviral prophylaxis and infant feeding counselling, and the benefits to infants of early diagnosis of HIV.<sup>186</sup>

Women, in particular pregnant women, because of their reliance on the health care system during pregnancy, are more likely to be affected by testing policies and

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<sup>181</sup> As above 36.

<sup>182</sup> Occasional paper 12.

<sup>183</sup> As above.

<sup>184</sup> RJ Cook & BM Dickens *Reproductive health and human rights: integrating medicine, ethics and law* (2003) 109.

<sup>185</sup> As above.

<sup>186</sup> As above.

their implications on human rights. A number of studies have addressed the risks of HIV testing for women, including women's fears of stigma, discrimination, abandonment, violence, expulsion from the home, and partner accusations of infidelity.<sup>187</sup> It has also been found that their fears concur with their reality of abandonment, loss of economic support, stigma, blame, and violence, upon disclosure of positive results.<sup>188</sup> Pregnant women, who may not have been seeking testing in the first place, may be unprepared to handle positive results if the minimum requirements for ensuring informed consent before HIV testing are not met.<sup>189</sup>

Finally, testing and disclosure could have the direst consequences in a climate of increased criminalisation of HIV transmission in Sub-Saharan Africa. Laws criminalising the 'wilful' transmission of, or exposure to, HIV have been enacted in a number of states throughout Africa,<sup>190</sup> including states in Southern Africa, and have been proposed in others, such as Malawi. The draft Malawian Bill states that 'any person who deliberately, recklessly or negligently does an act or omission that he knows or has reason to believe to be likely to infect another person with HIV commits an offence and shall be liable to imprisonment of 14 years.'<sup>191</sup> If passed, such a law can be used to punish mother-to-child-transmission of HIV. In fact, in other parts of Africa, similar laws have been passed, many of them criminalising exposure to HIV which, in effect, criminalises any HIV-positive woman who becomes pregnant regardless of whether the virus is transmitted to the infant.<sup>192</sup> Criminalising HIV transmission or exposure is clearly intended to deter women living with HIV from bearing children, constituting a violation of their reproductive health rights and further contributing to the discrimination and stigma they frequently suffer.<sup>193</sup> Furthermore, such laws have the potential to deter women from seeking antenatal care, particularly where mandatory or routine testing is imposed, and where knowledge of their status

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<sup>187</sup> Open Society Institute Law and Health Initiative *HIV testing during pregnancy: A literature and policy review* 2008 34 [http://www.soros.org/initiatives/health/focus/law/articles\\_publications/publications/hivtesting\\_20080916/hivtesting\\_20080731.pdf](http://www.soros.org/initiatives/health/focus/law/articles_publications/publications/hivtesting_20080916/hivtesting_20080731.pdf) (accessed 24 March 2009).

<sup>188</sup> As above.

<sup>189</sup> As above.

<sup>190</sup> Angola, Benin, Burkino Faso, Burundi, Cape Verde, Central African Republic, Chad, Democratic Republic of the Congo, Guinea, Guinea-Bissau, Kenya, Madagascar, Mali, Mauritania, Mozambique, Niger, Sierra Leone, Tanzania, Togo. <http://www.plusnews.org/InDepthMain.aspx?InDepthId=77&ReportId=81756> (accessed 25 May 2009)

<sup>191</sup> PlusNews 'Terrifying new HIV/AIDS laws could undermine AIDS fight' 7 August 2008 <http://www.plusnews.org/Report.aspx?ReportId=79680> (accessed 20 March 2009).

<sup>192</sup> P Eba 'One size punishes all' ALQ, Newsletter of the AIDS Legal Network September/November 2008 [http://www.icw.org/files/ALQ\\_Double\\_Edition\\_08\\_-\\_Criminalisation.pdf](http://www.icw.org/files/ALQ_Double_Edition_08_-_Criminalisation.pdf) The countries which have passed law criminalising exposure are Burkino Faso, Cape Verde, Central African Republic, Chad, Guinea, Guinea-Bissau, Mali, Mauritania, Niger.

<sup>193</sup> As above, 4.

can lead to commission of a 'crime'. As stated by one human rights advocate, 'why would a woman in Sierra Leone or Malawi or Tanzania want to have an HIV test that will, if positive, put her at risk of a jail sentence if she becomes pregnant, or the next time she has sex? The laws put diagnosis, treatment, help and support further out of her reach.'<sup>194</sup>

Botswana was the first African country to adopt a provider-initiated opt-out policy of HIV testing. One study noted that despite the increased number of pregnant women who were tested from the time the policy was adopted in Botswana, one-third of women tested in antenatal care clinics in one town did not return to the clinic to collect their test results.<sup>195</sup> This suggests they did not want the test in the first place and were not properly counselled before the test. This was confirmed in Malawi, where the majority of women interviewed confirmed that the testing policy provided for opting-out, but that in practice, testing pregnant women for HIV was done routinely without informed consent. Whereas less than 3% of adults in Malawi know their HIV serostatus,<sup>196</sup> it is highly likely that there is significant pressure to be tested. One woman spoke of her late young sister who was tested for HIV during pregnancy without her informed consent and without proper counselling. She did not return to the clinic for the result and avoided ante-natal treatment during her pregnancy so as not to have to repeat the test and therefore, was unable to access PPT services. She gave birth although neither she nor the baby lived long after. This is likely not an isolated case. Gains that may be made quantitatively from coercive testing scale up are lost in other more significant ways. This anecdote supports the contention of the International Guidelines, which note that 'coercive public health measures drive away the people most in need of such services and fail to achieve their public health goals of prevention through behavioural change, care and health support.'<sup>197</sup>

### **3.6 Forced or coerced sterilisation**

It has been suggested that the availability of antiretroviral treatment should be conditional on voluntary or enforced sterilisation after the present pregnancy, that termination of pregnancy should be considered in HIV-infected pregnant women, either

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<sup>194</sup> M Clayton, Director, AIDS and Rights Alliance for Southern Africa (ARASA) quoted in 'Southern Africa: HIV laws put women in the line of fire' *PlusNews* 1 December 2008 available at <http://www.plusnews.org/Report.aspx?ReportID=81723> (accessed 28 April 2009)

<sup>195</sup> SD Weiser et al 'Routine testing in Botswana: A population based study on attitudes, practices, and human rights concerns' (2006) 3 *PLoS Med* e261.

<sup>196</sup> Report card. HIV prevention for girls and young women. Malawi.

<sup>197</sup> Para 96.

voluntarily or by law, and that an Act of Parliament should be considered to the effect that all HIV-infected women in their reproductive years should be sterilised.<sup>198</sup>

Women have been subjected to a number of limitations to their reproductive autonomy in many countries for various reasons, but all policies claim to have found their basis on the collective good of the society. In Australia, for example, 1,045 girls with disabilities under the age of 18 were forcibly sterilized between 1992 and 1997 presumably owing to their disabilities.<sup>199</sup> Similarly, 19<sup>th</sup> century German law prohibited women who did not meet state-defined standard of racial purity from having children while at the same time prohibited women with desired racial purity access to abortion.<sup>200</sup> In India, women living with HIV have been coerced by health care providers to abort.<sup>201</sup> Such actions are contrary to international human rights law as outlined above.

Research carried out by the ICW documented 40 instances of coerced or forced sterilisation in Namibia, whereby informed consent was not adequately obtained. According to the ICW, 'consent was obtained under duress, consent was invalid as the women were not informed of the contents of the documents they signed, medical personnel failed to provide full and accurate information regarding sterilisation procedure.'<sup>202</sup> Women were also asked to provide signed consent for sterilisation in order to access other services including abortion and caesarean and to receive assistance with childbirth.<sup>203</sup> No incidences of coerced or forced sterilization were revealed through the limited field research undertaken in Malawi or Botswana for this study.

Compulsory sterilisation or abortion adversely affects women's physical and mental health, and infringes upon the right of women to control their fertility and to decide on the number and spacing of their children.<sup>204</sup> It violates other human rights,

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<sup>198</sup> BW Van de Wal 'Preventing perinatal vertical HIV transmission in South Africa' (1998) 88 *South African Medical Journal* 1283.

<sup>199</sup> See E Hastings 'Burning issues for people with disabilities' (1998) <http://www.wwda.org.au/hasting.htm> (accessed 10 March 2009).

<sup>200</sup> RJ Cook and S Howard 'Accommodating women's difference under the women's anti-discrimination convention (2007) 56 *Emory Law Journal* 1039, 1072.

<sup>201</sup> Center for Reproductive Rights Briefing Paper 'HIV/AIDS: Reproductive rights on the line (June 2002). See also T Delvaux & C Nostlinger 'Reproductive choice for women and men living with HIV: Contraception, abortion and fertility' (2007) 15(29) *Reproductive Health Matters* 53.

<sup>202</sup> International Community of Women Living with HIV 'Overview of ICW's work to end the forced and coerced' [sic] available at <http://www.icw.org/node/381> (accessed 04 February 2009).

<sup>203</sup> As above.

<sup>204</sup> CEDAW General Recommendation 19 par 22.

including the right to be free from cruel, inhuman and degrading treatment; the right to liberty and security of person, the right to bodily integrity; and the right to equality and to be free from discrimination. Restrictions on reproductive choice of women are bound to fuel discrimination and stigma against HIV-positive women subjecting them to double discrimination. Forced sterilisation, for example, will also lay additional favourable ground for further discrimination in societies which emphasise fertility and childbearing as a defining factor in women's successful contribution to the extended family and society as a whole. The International Federation of Gynecology and Obstetrics (FIGO), in outlining ethical considerations in sterilisation, stated that no incentives should be given or coercion applied to promote or discourage any particular decision regarding sterilisation. Withholding other medical care by linking it to sterilisation is unacceptable.<sup>205</sup> Because sterilisation is permanent, the decision made by the woman should be based on voluntary informed choice and should not be made under stress or duress.

## **5. Conclusion**

The drafters of the Universal Declaration, fundamental to the protection of dignity inherent in all human beings, had not heard of HIV and thought the greatest threat to human rights would be another world war. They could not have imagined the war that would be waged by HIV; that would attack those most vulnerable, including women and children. However, despite the nature of the war being other than what was envisioned, the Universal Declaration, and the subsequent body of human rights law it inspired, still offers the greatest defense. The spread of the virus will be significantly impeded, if not halted entirely, in societies where human rights are respected, protected and fulfilled. As highlighted above, stigma and discrimination, barriers to controlling one's fertility, unmet family planning needs and lack of access to contraceptive services, restrictive abortion laws, mandatory HIV testing, and coerced or forced sterilization, are all issues confronted by women living with HIV which threaten their human rights.

The study has noted the perception of HIV-positive women as 'vectors of the disease', especially when a pregnancy reveals their 'questionable judgment and morality' given that they had unprotected sex, risking transmission of the virus to themselves or their unborn children. Non-discrimination however, is enshrined in all major international human rights treaties and in all the Southern African constitutions.

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<sup>205</sup> FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health 'Ethical issues in obstetrics and gynecology' 2006 74.

States are therefore legally bound to protect their citizens from discrimination; yet, as the literature and field research demonstrate, state agents in the public health care system are frequently the perpetrators of discrimination against women living with HIV. National legal frameworks must be strengthened, guided by international human rights norms, to address HIV-related discrimination. At the same time, other non-legal measures, such as awareness-raising and education campaigns, must be undertaken towards the same end.

The freedom to decide whether or not to have children, and the number and spacing of children must be enjoyed by all women, including HIV-positive women in light of the additional challenges they face in this respect. Control over one's body and reproductive decisions however, implies empowerment and therefore, promoting the right to reproductive decision-making must take into account the reality of many women in Southern Africa. Often their 'usefulness' to society is determined by their ability and desire to reproduce, and the resultant pressure denies any reproductive choice at all. Also, in the region with some of the highest incidences of domestic and sexual violence in the world, women are unable to prevent unwanted pregnancies or assert control over their bodies. In order to create an enabling environment for women to exercise their right to control their fertility, intersecting factors such as inequality, and violence against women must be addressed through law and policy and accompanying implementation mechanisms with dedicated adequate financial resources.

The study also noted that preventing unwanted pregnancies naturally prevents HIV transmission to infants, and is more cost effective than PPT programmes. Despite this, many women living with HIV in Southern Africa have limited contraceptive options, if any, and are not fully informed of the risks and benefits of all available options. Also, given that women seeking family planning services are in their reproductive years, as are the majority of women living with HIV or at risk of infection, integration of family planning and HIV services is not only sensible, but necessary to effectively address the needs of the population group.

Women living with HIV and confronted with an unwanted pregnancy may want an abortion for a variety of reasons. Yet in all Southern African countries, except South Africa, their ability to access a safe, legal abortion is restricted, violating their right to autonomy. Often their right to life is also threatened whereby they seek illegal, unsafe abortions, which can have fatal consequences and have proven to be a major contributing factor to maternal mortality in the region. Reform of abortion laws is required throughout the region in order to enable women to exercise control over their

fertility through termination of pregnancy should they so desire. Where abortion is permitted where the women's life is at risk or to save the life of the mother or fetus, positive HIV status, should qualify for grounds to legally abort. However, in such cases, the choice to abort must be an informed one, made by the woman, without coercion or force.

It has been illustrated above that there exists a fine line between mandatory testing and provider initiated counselling and testing. Even in the case of the latter, where in principle, one can refuse the HIV test after counselling, in practice this is rarely the case. Either the option to refuse is not explained by the health care practitioners or, due to unequal power relationships between the patient and provider, the pressure to undergo testing in such a setting usually inhibits the right to refuse. Testing positive for HIV without having been properly counseled can have negative consequences. Disclosure of one's positive status can lead to partner violence or abandonment and destitution. At worst, it can lead to a prison sentence in countries where exposure to, or transmission of, HIV is a criminal offence. Mandatory, or routine testing where the requirements for informed consent, counselling and confidentiality are not met, is a coercive public health measure and violates human rights at the expense of a perceived 'greater good'. Countries must ensure protection of the human rights of all in the health care system and encourage voluntary counselling and testing while strengthening such services. Testing policies should be guided by the human rights principles enshrined in the International Guidelines, and be strengthened to include measures to mitigate the negative consequences for women of disclosure.

Another coercive measure also motivated by public health concerns relating to PPT is coerced or forced sterilisation. Two Namibian women are seeking redress in the High Court after being sterilised without their consent and advocates for the reproductive health rights of women living with HIV, along with positive-women's networks, should encourage other women to come forward who have had a similar fate and empower them to also file complaints. Impunity for such grave violations of reproductive health rights should not be tolerated. If local mechanisms are exhausted without success, then the cases should be brought before the African Commission on Human and Peoples' Rights or the CEDAW Committee.

In 2008, numerous events took place across the globe to commemorate the 60<sup>th</sup> anniversary of the Universal Declaration. Some were celebratory; others more somber, acknowledging that sixty years later, violations of human rights have not been curbed by the documented principles to which the nations of the world declared to adhere.

Only once these same nations realise that the protection of women's rights, not least health, warrant equal, if not greater resources to existing national priorities such as defence and security, will they receive a greater return towards peace and development and the ideals of the Universal Declaration will be fulfilled.

## **6. Recommendations**

Based on our research and findings the following actions are recommended:

- All Southern African states should draft a comprehensive rights-based reproductive health policy for women living with HIV, which includes contraception, including emergency contraception, accessibility and affordability of PPT measures; ongoing ART to ensure parents' survival; measures to help women deal with unwanted pregnancies including safe, legal abortion.
- HIV-positive women should be included in policy-making, implementation, and oversight concerning reproductive health care.
- Safe termination of pregnancy must be available and accessible, to the full extent allowed by law, to women living with HIV/AIDS who do not want to carry a pregnancy to term.
- Legislative reform should be undertaken, where necessary, with respect to restrictive abortion laws in order to create an enabling environment for safe, legal abortions for women living with HIV.
- HIV testing guidelines should be developed in accordance with human rights principles of informed consent and confidentiality. Voluntary counselling and testing should be the recommended testing regime. Where provider initiated testing and counselling is adopted it must not single out pregnant women and must be conducted under rigorous conditions of pre- and post-test counselling and the minimum information as outlined in the WHO Guidelines must be provided in order to ensure consent. Mechanisms for redress should be established if these conditions are not met.
- Human rights training must be provided, especially concerning the reproductive health rights of women living with HIV, to all health care professionals, specifically those who are involved in family planning, obstetrics and gynecology, and PPT programmes.
- Civil society must be supported to monitor government policies and performance on sexual and reproductive health issues.
- Men's involvement and participation in sexual and reproductive health services should be promoted towards the following goals: fostering positive behavior

change towards HIV prevention, and reducing the risk of partner infection or re-infection; mitigating the potential negative consequences of disclosure of positive test results; reducing the risk of STIs; educating and empowering men and women with information about family planning to prevent unwanted pregnancies, and encouraging communication and equality in reproductive decision-making.

- Ministries of Health should establish national procedures for reporting reproductive health rights violations, including forced or coerced sterilization and discriminatory treatment.
- Family planning counselling should be integrated into all phases of HIV care and treatment, including pre-test and post-test counselling and follow-up care. It should include an individual needs assessment in order to provide the most appropriate information.
- Southern African states that have not yet done so should ratify the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa. These countries are Botswana, Madagascar, Mauritius, and Swaziland.
- States should include in their periodic reports to international treaty bodies, in particular, the CEDAW Committee, the ICESCR Committee, and the African Commission on Human and Peoples' Rights, efforts taken to protect women's reproductive rights including reproductive choice and identify areas for improvement.
- International treaty bodies, in particular the CEDAW Committee, the ICESCR Committee, and the African Commission on Human and Peoples' Rights, should continue to include recommendations on reproductive health rights in their concluding observations to states.
- Relevant UN agencies such as UNFPA, UNIFEM and UNHCHR should provide technical assistance to states in promoting and protecting women's reproductive health rights, particularly with respect to women living with HIV.
- International donors must earmark funding for strengthening national programmes and services that support and protect women's reproductive health rights, particularly those that integrate HIV and reproductive health services.

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