# **Challenges faced by Women and Girls Living with or Affected by HIV in China**

Shadow report for the "UN Convention on the Elimination of all Forms of Discrimination against Women" (CEDAW)

15 August 2014

1.	Background
2,	, <b>Aim</b>
3.	Methodology
4.	Key findings
	4.1 The spread of AIDS across Chinese women is not optimistic. Female sex workers and nen of childbearing age are at high risk of HIV infection
	4.1.1 Chinese female AIDS epidemic on the rise, the male-female ratio is shrinking each
ye	ear 5
	4.1.2 Female sex workers are at high risk of HIV infection
	<b>4.2 Women receive HIV-related care, but the quality of coverage or service needs to be</b> roved
•	4.2.1 Detection and consultation service gradually improving, but the extent of women ceiving these services still needs to be improved
ne	4.2.2 Informing spouses reduces the risk of spousal transmission, but condom usage still eeds to be increased
ch	4.2.3 Antiretroviral therapy and follow-up coverage expanding year by year, but some nallenges remain
no	4.2.4 PMTCT work has made progress, but still requires standardization Error! Bookmark of defined.8
	4.3 HIV positive women still face serious stigma and discrimination
	4.3.1 Encounter prevarication and differential medical treatments in medication
	4.3. 2 Self-humiliation and employer discrimination coexist in employment
	4.3. 3 Children faced discrimination from schools and other parents
	4.3. 4 Serious self-humiliation, limited social interactions
	4.4 Policy and legal environment
	4.4.1 Related law on prevention and control of AIDS in China
ex	4.4.2 Weak sense of self-protection of rights using law and regulations, problem of sposure of privacy
	4.4.3 Some law, regulation, and AIDS prevention strategies are contradictory 100
5.	Conclusion
	Recommendation
6.	

# Content

# Abbreviations

AIDS	Acquired immunodeficiency syndrome (AIDS)
HIV	Human Immunodeficiency Virus
ARV	A Retrovirus
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CCW	Chinese communities infected women
FGD	Focus Group Discussion
PLWHA	People Living with HIV and AIDS
РМТСТ	Prevention of Mother To Child Transmission
VCT	Voluntary counseling and testing
PITC	Medical institutions providing testing and counseling
FSW	Female sex workers
WLHIV	Women Living with HIV

### 1. Background

The "Convention on the Elimination of All Forms of Discrimination against Women" (CEDAW) urges State Parties to overcome the structural obstacles faced in the elimination of discrimination against women in law, education, employment, medical assistance, and political and economic participation. China signed the Convention in 1980. Its latest submission to the CEDAW committee was the combined fifth and sixth periodic reports in 2004, which has been reviewed by the CEDAW Committee in August 2006. However, both the national report and the concluding remarks by the Committee at the time did not mention any issues related to women living with HIV.

More recently, the Government's seventh and eighth combined reports submitted to the Committee in 2012, mentioned specifically women living with HIV and their vulnerabilities. The government expressed significant concern for women living with HIV, especially in the area of mother-to-child transmission (MTCT).

## 2. Objective

The purpose of this shadow report is to provide the CEDAW committee more information on the current status of women living with HIV in China from the perspective of civil society organizations and women's groups. The further clarifies and emphasizes the current problems and challenges faced by Chinese women and girls living with or affected by with HIV and looks specifically into the situation of female sex workers affected by HIV. The goal of this report is to secure the better socio-economic protection and support for Chinese women and girls. We aim to attract the attention of the CEDAW Committee to have these issues reflected in the Committee's concluding observations. This report does not serve as a comprehensive review of the China's AIDS epidemic.

### 3. Methodology

The report is based on an extensive literature review and desk research combined with first hand information collected during two separate focus group interviews. The first focus group included 13 members of the Henan Women Network against AIDS, and the second one interviewed 16 representatives from Tianjin Xinai Cultural Communication Centre, all of whom were female sex workers. The interview questions were designed based on several findings from the literature review. All reference materials are available in the attached index section.

## 4. Key findings

Women and girls in China in comparison to men and boys lack information about sex, sexual and reproductive health, and specifically HIV-related health information and education. Poverty, violence, structural inequalities, social discrimination, adverse social and cultural environments, together with lower socioeconomic status, significantly increase the chance of HIV infection for women. Partly because of these reasons, women and girls in China are more vulnerable to HIV. Sexual transmission has become the main method of HIV transmission in China and the number of women affected with HIV is increasing. This report is prepared in the hope that the CEDAW Committee pay some attention to HIV-related issues to curb the spread of AIDS in China and to eliminate discrimination against women living with HIV. The ultimate goal of the report will be for the government to strengthen policies related to women

living with HIV and intensify its provision of services to women living with or affected by HIV.

# **4.1 Rates of HIV infection amongst Chinese women are increasing. Female sex workers and women of childbearing are particularly vulnerable to infection.**

# 4.1.1 HIV infection among women is on the rise, with the male-female infection ratio shrinking each year.

In recent years, the number of women who are infected or affected by HIV in China is on the rise, and this is having negative consequences on the overall national response to AIDS. Since 2007, sexual transmission has slowly surpassed drug use as the main mode of HIV transmission in China, becoming the main method of transmission, with an increase from 42.3% in 2007 to 89.9% in 2013. At the same time, this was accompanied by a clear increase over the same period in the number of new infections among women living with HIV. This increased from 14,633 in 2007 to 21,689 cases in 2012, representing an annual growth rate of 8.4% [1]. Among China's annual newly reported HIV cases, the proportion of male-to-female cases rose from 5:1 in the 1990s to 2.3:1 in 2009 [2]. Data on the female to male ratio of new HIV cases from Guangdong, Guangxi and Yunnan provinces show an increase from 12.5% 17.1%, 15.5% before 2000 to 23.6%, and 31.6%, 40.3% in 2009 respectively.

The overall HIV prevalence among female sex workers remains at a low level. The HIV infection rate over the years is lower than 0.5%. However, female sex workers are increasingly vulnerable to infection (see below) and in some areas the population of female sex workers living with HIV is increasing. For example, in the city of Guangzhou, Guangdong Province, HIV prevalence among female sex workers rose to 3.2% in 2003 [3].

In recent years, part of the National AIDS sentinel surveillance data has recorded more than 1% positive rate among pregnant women, which directly contributed to the danger of HIV infection among children [1].

Overall, the impact of AIDS on women's health is not only limited to reduced life expectancy, but also indirectly affects many other life aspects such as women's education, employment, and political status, etc. HIV infection is also one of the major risk factors that causes the deaths of women of reproductive age [6].

### 4.1.2 Female sex workers are at high risk of HIV infection.

Due to the increasing socio-economic disparity between rural and urban areas as well as rapid urbanization, a large proportion of the rural labor force, including women, has moved to urban areas in hope of better livelihoods. Because of many limitations faced by migrants in their work environments and their perceived lower social status, access to services and information resources is poor. This is especially true for marginalized female workers who have comparatively low levels of education, limited employment opportunities and meagre resources. Some of the women end up entering the sex industry, which places them into one of the highest risk groups for HIV infection in China<sup>[4,5]</sup>. In 1995, the Chinese CDC started to set up the first 12 locations for monitoring sex workers infections, which had increased to 157 locations by 2009. While overall HIV infection is increasing, the most worrying sign is the fact that consistent condom usage rates in the past month of commercial sexual activity is still

very low. The rate has increased from 10% in 1996 to 63.7% 2006, however its average is still only at 37.4% <sup>[6]</sup>.

Qualitative interviews showed that self-awareness about the risks of HIV infection amongst sex workers, especially low-income female sex workers, is still extremely low. They commonly relied on luck and, in order to earn money and conceal their identity, if the customer was unwilling to use a condom, they would still engage in risky sexual behavior with them. This situation is made worse by current local police regulations that treat condom possession as proof of sex work. As anti-prostitution raids by police in a number of provinces are intensifying, these regulations push female sex workers not to use or carry condoms on them. This is exacerbated by generally insufficient education on condom use, the lack of proper knowledge of condom functions which leads to sex workers often have difficulty requesting their clients to use condoms.

Due to inherent inequalities in power relations and strong criminalization of sex work, lowincome sex workers who are subject to abuse, sexual violence and exploitation are unwilling to seek help from the police, which leads to difficulties in protecting themselves and safeguarding their health. Most worryingly, due to societal shaming and sensitivity surrounding the industry, the majority of sex workers do not utilize condoms when engaging in sexual activity with their spouses, cohabiting or intimate partners, often for fear that this would lead to suspicion or judgment on their side. This is promulgating the risk of two-way infections and utilizing sex workers as a bridge to the general population.

#### 4.2 Quality and coverage of HIV-related services needs improvement

# **4.2.1** Detection and consultation services are gradually improving, but the number of women receiving these services should be improved.

At present, China has launched two HIV testing and consultation services: a voluntary counselling and testing (VCT) scheme and a provider-initiated testing and counselling (PITC) scheme provided by medical organizations and personnel.

From 2002 up to the present, China has set up over 6000 VCT locations, but the VCT coverage for at-risk groups (female sex workers, etc.) is proportionally low, with the most at-risk groups accounting for only 10.9% of all those who presented for testing. Apart from the Centre for Disease Control, Prevention Centre of Skin and Venereal diseases and community methadone maintenance and treatment clinics, other VCT institutions (medical, women and children, family planning, etc.) have usage rates below 50% <sup>[7]</sup>. Most importantly, a survey conducted in 2010 showed that the usage rates by men of VCT services in the four provinces and cities of Guangdong, Chongqing, Hubei and Henan were higher than those by women.

Aside from this, because part of the testing and counselling points were established in MCH or antenatal clinics, the users of these locations are almost all *pregnant women*; if we exclude this factor then, the real rate of women accessing voluntarily HIV testing and counseling is much lower.

Testing rates are especially low among female sex workers. Results from qualitative interviews showed that information regarding testing and counselling aimed directly at female sex workers is insufficient and that intervention coverage and intervention efforts are sorely lacking, especially amongst low-income sex workers. This increases their own as well as their partners' vulnerability to HIV.

# **4.2.2** Informing spouses reduces the risk of spousal transmission, but condom usage still needs to be increased.

Spousal transmission is an important channel for sexual transmission of HIV and represents a larger threat to women than men. Amongst women living with HIV in China, 31.7% reported having been infected by their spouse, whereas for male heterosexual carriers this proportion was only 6.8%. In certain areas, there is a clear upward trend in the proportion of women infected by their spouses. For example in Guangdong, Guangxi, and Henan the proportion of females who had been infected by their spouses or intimate sexual partners grew from 7.2%, 16.7% and 42.9% respectively in 2001 to 49.8%, 42.4% and 60.8% in 2009<sup>[8]</sup>.

Informing spouses is a measure to prevent and control the spread of HIV through changing the behavior of individuals and groups and is, to some extent, an efficient way to prevent instances of secondary infection<sup>[17]</sup>. China has instituted policies regarding informing spouses in some regions <sup>[18-22]</sup>, aimed at encouraging people living with HIV to inform their partners. These policies have played an important role in supporting spouse-informing initiatives, and have raised people affected by HIV and patients' knowledge <sup>[23]</sup>. According to the results of surveys carried out in six counties and cities in Yunnan, Henan, Sichuan, Guangxi, and Chongqing, the spousal informing rate of females living with HIV and patients stood at 63.9%, higher than that for males living with HIV (47.6%)<sup>[24]</sup>.

Supporting the correct usage of condoms can also be an efficient method of preventing the spread of HIV<sup>[25, 26]</sup>. As research shows, condom usage by men living with HIV in the past 3 months of sexual activity with their intimate sexual partners stood at only 48.9%<sup>[8]</sup>. After learning of their spouse's infection, 86.9% indicated that condom use increased during sex with their spouses but the rate of those who used a condom every single time they had sex stood at only 56.6%. Most worryingly, there were still 12.1% of the survey respondents who said they never used condoms when engaging in sexual activity with their partners, illustrating that the HIV transmission risk from spouses is still relatively high<sup>[27]</sup>. Under the constraints of the traditional concept of sex, not only do women occupy a lower status in sexual matters – passive and vulnerable – but also their basic grasp and knowledge of sexually transmitted diseases and HIV is comparatively weak and their ability to use condoms undermined. The majority of women are only found to be living with HIV during the course of pregnancy and childbirth or after developing AIDS themselves.

# 4.2.3 Antiretroviral therapies and follow-up coverage expanding year by year, but some challenges remain.

According to the 2011 AIDS epidemic evaluation report, as of September 2011 there was a national total of 133,524 people receiving free antiretroviral treatment in China. Coverage for antiretroviral treatment rose from 62.0% in 2009 to 73.5% at the end of September 2011. There was no discernible difference in men or women receiving ART. Results of the National Eleventh Five-year plan for major science and technology research verified that antiretroviral medication can reduce the risk of transmission in an HIV-discordant couple by 66%. Relevant statistics shows that for "discordant families," in which one partner is positive, the rate of antiretroviral coverage rose from 44.9% in 2010 to 58.1% in 2011. Even though this made more progress in 2012, the total rate still stands at only 64.8%.

Comprehensive follow-up and management of HIV patients needs to be improved. The proportion of Chinese HIV patients receiving standardized follow-ups and CD4 counts has increased from 78.5% and 62.5% respectively in 2009 to 84.3% and 72.7% in 2011. At

present, results of quantitative interviews show that respondents are comparatively satisfied with follow-up services. However access to this services remains an issue in certain areas and female patients state that communication is easier and leads to potentially better results when NGOs or independent organizations are conducting the follow-ups.

### 4.2.4 PMTCT work has made progress, but still requires standardization.

In order to reduce the risk of mother-to-child transmission, China established dedicated centres in 2002. In 2006, the Ministry of Health produced the "Guidelines for strengthening PMTCT" and in 2008 revised the national "Programme for implementing PMTCT." In 2011, the Ministry issued the "Notice of the published 'prevention of AIDS, syphilis and hepatitis B MTCT implementation'," which further expanded the work of PMTCT services and integrated prevention of AIDS, mother to child transmission of syphilis and hepatitis B to form a more robust PMTCT policy.

In 2011 HIV counseling and testing services were provided to over eight million pregnant women, with testing rates reaching 92.9%. The proportion of HIV positive pregnant women who received antiretroviral treatment stood at 74.1% and with infant antiretroviral medicine use reaching 85.2%. The rate of babies born with HIV from an infected mother stood at 7.4%, a decrease from 8.1% in 2009, but the proportion of pregnant women who are both HIV positive and using infant antiretroviral drug still needs to be increased and standardized.

### 4.3 HIV positive women still face serious stigma and discrimination.

According to the report of the "China HIV Discrimination Survey" published in December 2009 by UNAIDS, there was a substantial percentage of those in the medical industry (26%), government workers group (35.3%) and professors group (36.2%) who displayed either 'discriminatory' or 'strongly discriminatory' attitudes or behaviors towards individuals after learning of their HIV status. In 2013, a survey on discrimination against people living with HIV was conducted in seven Chinese provinces with a total of 514 HIV positive women interviewed. After contracting HIV, women who felt stigmatized and suffered from low self-esteem stood at 61.3% and 54.9% respectively.

Finally, psychologically, HIV positive women face numerous concerns, with the percentages of those fearing verbal abuse, fearing about being talked about, fearing rejection, fearing losing friends, and fearing loss of social occasions like meals with colleagues standing at 71.6%, 89.1%, 80.7%, 73.3% and 65.6% respectively. As such, HIV positive women still face a serious degree of stigma and discrimination.

### **4.3.1 Discrimination in health-care settings**

Discrimination or prejudice against people living with HIV is serious, especially with regards to their medical treatment [38]. There are occasional reports that women living with HIV have found it difficult to be treated by doctors or to receive surgery. In some places, there have even been circumstances where patients have been sent back and forth, resulting in negative health impacts and even led to life-threatening situations [40]. The results of a survey conducted in four Chinese provinces on 100 female AIDS patients showed that 20% believed that they were subject to discrimination by medical staff because of their HIV status and sex [41].

Qualitative interviews have also shown that survey participants have experienced doctors who used different excuses to hesitate on treatment, covertly refuse treatment, or conduct alternative treatment. Due to discrimination, some people choose to give up treatment, or opt for less reputable and informal small clinics. Discrimination or prejudice against women with HIV is serious, especially healthcare settings.

### 4.3. 2 Discrimination in employment settings

A study in 2013 about discrimination towards women living with HIV revealed that, among 876 women, 8.4% were fired by their employers, 6.4% resigned because of pressure from themselves, 2.7% were rejected employment during job seeking because of HIV, 2% lost promotion opportunities, and 38.5% had simply given up applying for certain jobs.<sup>[39]</sup>

Qualitative interviews show that women living with HIV are afraid of exposing their status because of bad health and the side effects of treatment and worry that this will difficulties in their work environments. These pressures move some women to voluntarily resign but in most cases women living with HIV loose promotion opportunities and often get fired because of their HIV status.

#### 4.3.3 Strong social stigma leads to self-stigma

Women who live with HIV/AIDS have their social activities largely influenced by the severe shaming and sense of inferiority that they receive from the discrimination and isolation from family and society. A study in 2013 about discrimination towards those with HIV revealed that, among females, those who avoided social activities, kept a distance with relatives and friends, worried about employment physical check-ups, afraid to seek jobs, moved because worried that neighbors would find out and thus did not dare to go to hospital/clinics when sick were 59.9%, 51.4%, 30.4%, 19.5%, and 28.2% respectively.<sup>[39]</sup>

Qualitative interviews also found out that the relatives, colleagues and neighbors were reluctant to interact with women after they knew they were HIV positive. Isolations made it difficult for them to lead a normal life.

#### 4.3.4 Impact on women's reproductive health, family life and domestic violence

Several studies on Chinese women living with HIV show how between 11% and 15% of women who are married or have intimate sexual partners go through forced abortions enacted by medical personnel or birth control departments. While more data on this phenomenon needs to be created, we do know that 43.5% of medical personnel believe that HIV positive pregnant women should have forced abortion or sterilization<sup>[42]</sup>.

Qualitative interviews show that in a family with one HIV positive member, HIV negative women are subject to unsafe sexual behavior, and therefore run a higher risk of HIV transmission. On the other hand, when the woman happens to be positive she is often forced to divorce because of her HIV status, and often suffers from emotional and physical abuse and violence. Some have indicated that, even if the woman does not divorce, the family would keep a distance and isolate her in daily life.

#### 4.4 Protective regulations and laws are relatively solid, but their implementation is weak.

#### 4.4.1 Relevant laws on AIDS prevention and control in China.

Both the "*Law on the Prevention and Treatment of Infectious Diseases*" revised by NPC in 2004 <sup>[43]</sup> and the "*Regulation on the Prevention and Treatment of AIDS*" approved by the State Council in 2006 <sup>[44]</sup> stipulate that any employer or individual should not discriminate against HIV positive people and their relatives. The administrative regulations from 2006 also stipulate the marriage, employment, healthcare, education and other legal rights of HIV positive people. A series of other national laws, regulations, prevention, and treatment plans all address the importance of preventing female infections and protecting the rights of women living with HIV.<sup>[45-51]</sup>

General laws that are suitable for HIV- related rights in China include<sup>[52]</sup>: law on blood and blood products<sup>[53-55]</sup>; law on drug and drug usage<sup>[56]</sup>; law on sex and marriages<sup>[57]</sup>; law on the protection of women's rights<sup>[58]</sup>; law on maternal and infant health<sup>[59]</sup>; law on social security such as health, social welfare, and legal aid etc.<sup>[60]</sup>; and the law relating to education and employment (with possible discrimination)<sup>[61-63],</sup> etc.

#### 4.4.2 Right to Privacy and general legal literacy

Studies have found that people living with HIV often do not seek help from the government or society in order to avoid perceived stigma and discrimination<sup>[64]</sup>. Only 5% of people living with HIV would consider using legal aid services, for example. The main reason not to apply for legal aid is their worry about revealing their identity to the public during legal proceeding or even legal consultations<sup>[52]</sup>. More generally, most women affected by HIV from rural areas and ethnic minority regions barely know about HIV prevention and treatment and even less about the relevant laws and regulations in place to protect them <sup>[65]</sup>.

Most importantly. although the law clearly stipulates that relevant organizations should protect the privacy of HIV patients, in reality privacy remains as a significant issue. Interview results from the research team have shown that some medical professionals have a weak sense of the law and often compromise the privacy of women. In instances such as public housing application, petition, and medical care, responsible organizations did not protect the privacy of the patients and personal information was then leaked out.

#### 4.4.3 Contradictions in laws, regulations, and AIDS prevention strategies.

There exist large contradictions among laws, regulations, and AIDS prevention strategies, such as in: *the strategy for effective AIDS prevention, treatment, care, and support for sex workers; The Penal Code*<sup>[66]</sup>; *Law on the Administrative Punishment of Public Security*<sup>[67]</sup>, *NPC Standing Committee's Decision on Prohibiting Prostitution*, <sup>[68]</sup> and *State Council's Notice on Further Strengthening AIDS Prevention*<sup>[69]</sup>. In general, while all HIV-related strategies and policies focus on protecting the rights of PLHIV, including women, all the above-mentioned laws and policies contain clauses on combating illegal prostitution and licentiousness activities. These criminal laws are better enforced than AIDS regulations and lead to a scenario where HIV-related policies are ignored for the benefit of public security. Two additional examples of such discrepancies are related to household registration and working for the civil service. China has a huge population migrating between rural and urban areas and among different cities. While most HIV policies push for nation-wide free and accessible treatment services, some other regulations force people to access medical services (or any other social service) in their local household registration area. This has prevented many people, especially women, from receiving treatment. Also, while most AIDS policies

have anti-discrimination clauses in employment settings, the national civil service still has a requirement for an HIV test as part of their final entry-level exam. HIV-positive people are not allowed to join the civil service.

Additionally, qualitative interview has shown that the police use condoms as evidence of sex work during anti-pornography campaigns. This policy has made the popularization and awareness campaign for condoms more difficult and has increased the vulnerability of women to HIV. Therefore, relevant law and regulations need to be improved to build an environment that is conducive for effective AIDS prevention.

Finally, although a series of policies and laws address the importance of preventing female infections, at the implementation level there is currently insufficient action towards this goal. For example, we have yet to see any state-sponsored analysis or surveys on the current prevention strategies of female infections <sup>[70]</sup>; the national AIDS prevention budget does not have a budget specific for prevention activities among women, and there are no prevention strategies targeting specifically females, such as the promotion of female condoms.

### 5. Conclusions:

**5.1** The HIV epidemic among women in China is on the rise, with the male-female ratio shrinking, and women being increasingly affected by AIDS. Female sex workers are particularly vulnerable to HIV infection and are not aware of the risks and means of protecting themselves. This is shown by the fact that condom use remains extremely low. Strategic information, health checks and consultations for female sex works are weak, breadth and depth of interventions is insufficient.

**5.2** Women living with HIV are still facing serious discrimination and humiliation in health care, employment, and education settings. Social stigma is extremely high and denies women normal social interactions and lives. HIV status has a huge impact on women's reproductive health and family life. Domestic violence against them is pervasive and phenomena such as forced abortions are still too common.

**5.3** Women are able to access most HIV-related services, but voluntarily acceptance of consultations and testing is low. Treatment, follow-up, and maternal and infant care have increased coverage, but the ratio of treatment needs improvement and standardization. The role of female-led community organizations and NGOs in AIDS prevention needs to be strengthened.

**5.4** Although HIV sensitive laws and regulations exist, their implementation is weak. Strong criminal laws against prostitution are better enforced and are having a negative impact on the response to HIV. In particular, local police regulations that use condom possession as proof of sex work push most female sex workers not to carry or use condoms. Most women who are discriminated because of their HIV status have a weak sense of using laws and regulations to defend their rights. Some aspects of the laws, regulations, and AIDS prevention strategies are contradictory, and social gender sensitivity and effective measures preventing HIV infection for women need to be strengthened.

### 6. Recommendations

**6.1** The government needs to redouble its gender sensitive efforts in the prevention of HIV among women, support a national analysis of current trends and develop specific responses targeting women living with or most vulnerable to HIV. A new HIV prevention strategy

focusing on women needs to be adopted and be supported by an increase in specific budgetary support.

**6.2** Provide financial, technical and political support to NGOs and make full use of their ability to reach vulnerable women. Especially community organizations that are female-led and support and care for female sex workers and women living with HIV. Develop new HIV prevention information and intervention services, especially regarding testing, follow-up care, and specifically for high-risk groups such as female sex workers. Provide stronger social care and support for HIV positive women.

**6.3** Further facilitate a social environment with less or no discrimination for women living with HIV. Prohibit hospitals from refusing treatment or discriminating against them. Implement and improve relevant regulations, strengthen monitoring and law-enforcement of these. Reform some of the outdated public security regulations that are negatively impacting the national AIDS response and vulnerable women.

### Annex 1 - CEDAW articles that relate to women living HIV:

• Article 1: Eliminate definitions which discriminates women;

• Article 2: Demand State Parties to condemn all forms of discrimination against women, to establish a legal framework in order to provide protection to eliminate discrimination of women and ensure equality

- Article 11: State Parties shall adopt appropriate measures to eliminate discrimination against women in the field of employment in order to ensure, on the basis of equality of men and women, the same right to work, employment opportunities and equal remuneration; the right to free choice of profession and employment; the right to social security; the right to protection of health and to safety in working condition, including the safeguarding of the function of reproduction.
- Article 12: States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on the basis of equality of men and women, access to health care services, including those related to family planning.
- Article 14: States Parties shall take all appropriate measures to eliminate discrimination against women in rural areas, ensure to such women the right to have access to adequate health care facilities, to benefit directly from social security programmes, to enjoy adequate living conditions.
- Article 16: States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relation to ensure women enjoy the same right to enter into marriage; the same rights and responsibilities during marriage and at its dissolution; the same rights to decide freely and responsibly on the number and spacing of their children; the betrothal and the marriage of a child shall have no legal effect.
- Article 18: States Parties undertake to submit to the Secretary-General of the United Nations, for consideration by the Committee, a report on the legislative, judicial, administrative or other measures which they have adopted to give effect to the provisions of the present Convention and on the progress made in this respect

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