

An abstract graphic featuring three stylized faces in shades of brown and blue. Overlaid on the faces are various text elements in a light blue, semi-transparent font: 'DISCRIMINATION' on the left, 'VIOLENCE' at the top, 'ARBITRARY DEPORTATION' on the right, and 'SEXUAL VIOLENCE' on the right side. A large, stylized blue hand is positioned in the center, with a red ribbon (HIV/AIDS symbol) draped across it. The background is a dark blue gradient.

HUMAN RIGHTS ISSUES CONFRONTED BY HIV POSITIVE WOMEN IN JAMAICA



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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CARICOM	Caribbean Community
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CHARES	Centre for HIV/AIDS Research, Education and Services
CIDA	Canadian International Development Agency
CRC	Convention on the Rights of the Child
EC	European Commission
ECLAC	United Nations Economic Commission for Latin America and the Caribbean
ECOSOC	United Nations Economic and Social Council
GIPA	Greater Involvement of People Living with HIV
HIV	Human Immunodeficiency Virus
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICW	International Community of Women living with HIV/AIDS
JASL	Jamaica AIDS Support for Life
JCW	Jamaica Network of Women Living with HIV
JN+	Jamaica Network of Seropositives
MoH	Ministry of Health
MSM	Men who have Sex with Men
NAC	National AIDS Committee
NACA	National Agency for the Control of AIDS
NHP	National HIV/STI Programme
NGO	Non-Governmental Organization
NSP	National Strategic Plan
PLHIV	Persons Living With HIV
PMTCT	Prevention of Mother to Child Transmission
PWMC	Positive Women Monitoring Change
STI	Sexually Transmitted Infection
SW	Sex Worker
TCI	Targeted Community Interventions
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Children's Programme
UNGASS	United Nations General Assembly Special Session on HIV and AIDS
UNIFEM	United Nations Development Fund for Women



1. EXECUTIVE SUMMARY



This report supports the implementation of the UN Women (*formerly UNIFEM*) - European Commission Project entitled: *Supporting Gender Equality in the Context of HIV and AIDS*. The overall objective of this programme is to ensure that gender equality and human rights are integrated into key policies, programmes and actions to address HIV/AIDS at the national level. The specific objectives are: (i) to promote the leadership and participation of HIV-positive women's organizations and women affected by HIV/AIDS in shaping the policies, programmes, and resource allocations that address the HIV/AIDS epidemic in 5 selected countries (Kenya, Rwanda, Cambodia, Papua New Guinea, and Jamaica); and (ii) to develop core capacities of national AIDS coordinating mechanisms to promote human rights and gender equality in the HIV/AIDS response in Jamaica.

This report assesses the human rights issues confronting Jamaican women infected and affected by HIV/AIDS with specific focus on the political and civil and economic, social and cultural rights. This report further identifies the human rights policies and programming by state and non-state actors in meeting state obligations to protect, respect and fulfil human rights in Jamaica. The report also examines the compounded vulnerabilities to human rights violations experienced by women and identifies emerging strategies and best practices that address human rights violations. The report ends with recommendations for strategic directions and priorities that Jamaica should adopt to ensure that women infected and affected by HIV/AIDS secure the full enjoyment of their human rights.

This report represents the voices of women infected and affected by HIV/AIDS in Jamaica. Their issues are documented as explained by them and the recommendations made are based on their input.

Methodology

This report was informed by in-depth interviews with over fifty key informants such as representatives of organizations working with women infected or affected by HIV and AIDS, women's organizations, HIV advocacy and outreach organisations, women infected and affected by HIV/AIDS, health care workers, and also women who were unaware of their HIV status. The analysis was also informed by extensive literature review of human rights instruments, national strategic plans and frameworks and existing studies on the status of persons living with HIV and AIDS.

The primary methods of data collection were semi-structured one-on-one interviews and focus groups, which focused on the issues affecting women who are infected or affected by HIV/AIDS. HIV positive women were asked about their experiences since diagnosis of the infection with respect to health care, employment, education and training, family and community relations and intimate relationships. They were also asked about their views on the adequacy of the present national HIV/AIDS response and societal norms towards HIV positive women. For each issue identified by the women, the women were encouraged to provide recommendations as to what could be done to help address that issue.

Health care workers, HIV/AIDS support workers, representatives of policy development departments and women's organizations were asked to outline their strategies with respect to women infected and affected by HIV/AIDS. They were specifically asked about the human rights concerns of HIV positive women as was highlighted by the HIV positive women. They were further invited to make recommendations for improving the human rights situations of women infected and affected by HIV/AIDS in Jamaica.

The sample

There was purposive sampling of HIV/AIDS support organization staff and clients. Key informants were identified and recruited in consultation with Jamaica AIDS Support for Life, CHARES, Eve for Life and JN Plus. There were 13 professional informants composing of 2 doctors, 3 social workers and 8 persons who worked as counsellors, HIV/AIDS facilitators, programme coordinators/managers and administrators. The support organization clients who were interviewed consists of 28 HIV positive women from urban and rural Jamaica, one HIV negative sex worker and one HIV negative transgendered person. The youngest HIV positive interviewee was 19 years-old and the oldest was over 50 years of age. All of the HIV positive persons, sex workers and the transgendered person interviewed gave their consent to participate in the study and duly signed the consent forms before the interviews began.

Key findings

Existing studies on the status of persons living with HIV/AIDS point to a direct relationship between gender inequality, human rights violations and the prevalence of HIV/AIDS. The research carried out in Jamaica reveals that gender inequality and human rights violations help to fuel the spread of HIV/AIDS and worsen the socio-economic and health situations of women infected or affected by HIV/AIDS in Jamaica. The information gathered from the interviews conducted disclose that the main human rights issues confronting women infected and affected by HIV/AIDS in Jamaica are: discrimination and stigma; inadequate access to health care; low quality of health care; breach of the rights to privacy and confidentiality; violence; gender inequality; infringement of sexual and reproductive rights; inadequate access to accurate HIV related information and arbitrary dismissal from work.

Recommendations

The actionable recommendations for state and non-state actors who are involved in the national HIV/AIDS response so as to effectively address the human rights violations of women infected and affected by HIV/AIDS are outlined as follows:

1) Improving the National HIV/AIDS Response by:

- a) adopting a rights-based approach to HIV/AIDS
- b) adopting gender mainstreaming as part of the national HIV/AIDS strategy
- c) employing a multi-sectoral approach in addressing the human rights issues relating to the HIV/AIDS epidemic
- d) ensuring effective participation of women infected and affected by HIV/AIDS in the national HIV/AIDS response
- e) educating the public about issues surrounding gender equality, HIV/AIDS and human rights
- f) involving men in the national HIV/AIDS response

2) Improve the legal framework in relation to HIV/AIDS by:

- a) amending the Constitution of Jamaica to ensure the effective protection and enforcement of human rights
- b) undertaking legislative reform to: (a) address the invisibility of HIV positive women in the law, particularly violence against HIV positive women; and (b) provide for compensation for survivors of sexual violence


3) Strengthen state accountability by having mechanisms in place to hold the State accountable for violation of the human rights of HIV positive women

4) Strengthen support for women infected and affected by HIV/AIDS by:

- a) empowering women and their families to deal with the HIV-related issues which affect the family unit
- b) improving access to and the quality of health care for women infected or affected by HIV/AIDS
- c) recognizing that at present the efforts are wholly inadequate and a greater emphasis must be placed on personal responsibility



2. HIV/AIDS AND HUMAN RIGHTS POLICIES AND PROGRAMMING BY STATE AND NON-STATE ACTORS IN MEETING STATE OBLIGATIONS TO PROTECT, RESPECT AND FULFIL HUMAN RIGHTS



On March 31, 2010 Jamaica submitted its country progress report (prepared by the National HIV/STI Programme, Ministry of Health) to the Secretary General of the United Nations on the United Nations General Assembly Special Session (UNGASS). It is this most recent country progress report which largely informs this documentation of the HIV/AIDS and human rights policies and programmes adopted in Jamaica to help protect, respect and fulfill human rights.¹ It is evident from this most recent country progress report that there is room for strengthening gender equality considerations in the national HIV/AIDS response.

With respect to the policies and programming in place to help support and protect human rights, the country progress report pointed out that the ‘ratings for efforts in implementing policies, laws and regulations for Human Rights have remained relatively lower than other areas over the period’. This was the finding from the *National Composite Policy Index – Trend Analysis* which was conducted biannually from 2003 to 2009 from surveys of representatives from civil society organizations, bilateral agencies and UN organizations.²

According to the country progress report, Jamaica’s national response to the HIV epidemic focused on four priority areas. These are: prevention; treatment, care and support; enabling environments and human rights; empowerment and governance. The national response saw the introduction of antiretroviral treatment in 2004 and the expansion of HIV programmes including efforts to reduce mother to child transmission of HIV.

With respect to the policy and legislative framework for prevention and treatment of HIV, the report highlighted the following:

- National Policy for the Management of HIV/AIDS in Schools was approved by the Parliament
- National HIV/AIDS Policy approved
- National HIV/AIDS Workplace Policy accepted by a Joint Select Committee of Parliament
- Manual on Life Threatening Illnesses, including HIV/AIDS was developed
- Jamaica Business Council on HIV/AIDS was created in 2006
- National HIV-Related Discrimination Reporting and Redress System was established in 2007

¹ Report available at <data.unaids.org/.../Report/2010/jamaica_2010_country_progress_report_en.pdf>

² National HIV/STI Programme, Jamaica, UNGASS Country Progress Report 2010, p. 33, available at <data.unaids.org/.../Report/2010/jamaica_2010_country_progress_report_en.pdf>

- A National Multi-sectoral Group was created since 2007 to offer guidance and recommendation for the functioning of the National HIV-Related Discrimination Reporting and Redress System. This group includes organizations such as:
 - Jamaica Network of Seropositives
 - The Jamaica AIDS Support for Life
 - National HIV/STI Programme
 - National AIDS Committee and its Legal and Ethical Sub Committee
 - Independent Jamaica Council for Human Rights
 - Resident Office of the Joint United Nations Programme on HIV/AIDS
 - Direct representation from the community of persons living with HIV and AIDS
- Positive public statements from the Prime Minister of Jamaica that old laws such as the Quarantine Act, the Venereal Diseases Act and the Leprosy Acts should be abolished.

The intervention strategies employed by the State to prevent the sexual transmission of HIV include:

- Targeted Community Interventions (TCIs)
- Targeted interventions among key populations at high risk
- Media campaigns
- Sports interventions
- Cultural vehicles (talent search competitions, party intervention strategy, having peer educators on public buses)
- Establishment of new non-traditional condom outlets (taxi drivers, influential persons at night clubs, community advocates)
- Expansion of HIV testing
- Partnering with key line ministries (NGOs, faith-based organizations, private sector)
- Greater involvement of people living with HIV (GIPA)



3. HUMAN RIGHTS ISSUES CONFRONTED BY WOMEN INFECTED AND AFFECTED BY HIV/AIDS

3.1 HUMAN RIGHTS FRAMEWORK

The development in the global response to HIV/AIDS is the recognition that the HIV/AIDS epidemic demands a rights-based response. It has been repeatedly emphasized that full realization of human rights and fundamental freedoms for all is an essential element in the response to the HIV/AIDS pandemic.³ In Jamaica, the Constitution of Jamaica, as well as international and regional human rights instruments provide the normative legal framework for recognition and enforcement of human rights. International and regional human rights instruments in this regard include:

- The Universal Declaration on Human Rights (1948)
- The International Covenant on Civil and Political Rights (1966)
- The International Covenant on Economic Social and Cultural Rights (1966), Committee on Economic, Social and Cultural Rights, General Comment No. 14 on 'The right to the highest attainable standard of health'
- The Convention on the Elimination of all Forms of Discrimination against Women [CEDAW] (1979) , Committee on the Elimination of Discrimination against Women, General Recommendation No. 24, 'Women and Health'
- The Convention on the Rights of the Child (1989), General Comment No. 3, 'HIV/AIDS and the rights of the child'
- Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women "Convention of Belém do Pará) 1994

Special attention has been paid to HIV/AIDS at the international level by virtue of:

- UN General Assembly Special Session (UNGASS) on HIV/AIDS Declaration of Commitment (2001)
- Millennium Development Goals (2000)
- Fourth World Conference on Women [Beijing] Declaration and Platform for Action (1995) and Article 3 of the Beijing +5 Outcome Document (2000)
- International Conference on Population and Development Programme of Action (1994)
- World Conference on Human Rights Declaration and Programme of Action
- International Guidelines on HIV/AIDS and Human Rights
- UN General Assembly Resolutions⁴

³ See for example UN General Assembly Resolution 58/236 of 25 February 2005

⁴ See for example Resolution 58/236 adopted on 25 February 2005 and Resolution 2003/47 of 23 April 2003

For women infected and affected by HIV/AIDS, the following civil and political and economic, social and cultural rights are especially important:

Under the International Covenant on Civil and Political Rights (ICCPR)

- The right to life
- The right to liberty and security of the person
- the right to privacy and its protection under the law
- the right to equality before the law and equal protection
- the right to marry and found a family
- the right to be free from torture and other cruel, inhuman or degrading treatment or punishment
- the right to freedom of association

Under the International Covenant Economic, Social and Cultural Rights (ICESCR)

- The right to work
- The right to the highest attainable standard of mental and physical health
- The right to equal access to education

Human rights issues affecting women living with HIV/AIDS in Jamaica manifest themselves in the following areas:

- Health care
- Privacy and Confidentiality
- Stigma and Discrimination
- Violence
- Access to Information
- Sexual and Reproductive Rights
- Work/Employment
- Equal Protection of the Law



3.2 HEALTH CARE

3.2.1 ACCESS TO HEALTH CARE

While efforts are being made by the State to provide adequate health care and treatment to women who are infected with HIV/AIDS, information gathered from the research conducted shows that there are significant barriers to women's access to health care. The barriers range from the reluctance of women to seek health care services to the poor attitude of health care workers towards HIV positive women.



A significant number of HIV positive women interviewed indicated that when they were made aware of their HIV positive status they were reluctant to seek health care from the state-run health care facilities.

Delay in seeking treatment

A significant number of HIV positive women interviewed indicated that when they were made aware of their HIV positive status, they were reluctant to seek health care from the state-run health care facilities. Some waited for many years until they really felt ill and had obvious signs of being sick such as rapid weight loss, frequent and prolonged diarrhea, excessive rashes on skin, fever etc. before seeking treatment. Others sought treatment only upon discovering that they were pregnant in order to reduce the risks of transmission to their babies. The reasons that the women gave for delaying seeking treatment are:

- Fear of stigma and discrimination by health care providers
- Fear that their status would be disclosed to community members, co-workers, family members and intimate partners
- Fear of being scorned, ridiculed and blamed for having contracted HIV
- Fear of violence from intimate partners and family members
- Lack of knowledge on what the care and treatment included
- Being in denial about one's status as they looked and felt healthy
- Lack of family and social support
- Child care and family responsibilities

Cultural barriers

It was found that there are cultural barriers which impede women's access to health care. While it is generally accepted that women in Jamaica are more willing to seek health care services than men; the research findings demonstrate that with respect to HIV/AIDS women are generally reluctant to access health care services. Majority of the HIV positive interviewees indicated that they were reluctant to have an HIV test done, collect HIV test results and to seek treatment and counselling. The women explained that in many of their communities, once it is known that a person did an HIV test, there is strong suspicion that the person is HIV positive as the misconception is that only persons who believe that they are HIV positive have the test done.

Transportation costs

What is clear from the research conducted is that the financial constraints of HIV positive women have a direct effect on their access to health care and also the quality of health care they receive. The women revealed that oftentimes they do not keep their health care appointments because they cannot afford the transportation cost to the health care facility.

Treatment of opportunistic infections

Most of the interviewees indicated that they were provided with very little information about opportunistic infections and how these may be treated. Even when they had taken the initiative to ask their health care providers they were not provided with adequate information in a way in which they could understand. The consequence of this is that many HIV positive women were not aware of how to deal with opportunistic infections and oftentimes delayed in seeking treatment for them.

Some of the interviewees felt shame in seeking treatment for opportunistic infections. They therefore hid the true nature of their medical concerns especially when it involved a gynecological condition. Others specifically tried to withhold their HIV status from their health care provider when seeking treatment for an opportunistic infection. The interviewees explained that they anticipate that they will be judged and treated in a discriminatory manner if their HIV status is disclosed. To prevent this, some interviewees sought treatment for opportunistic infections at a different health facility from which they receive their HIV medications or from where they were diagnosed.

Oftentimes the women do not keep their health care appointments because they cannot afford the transportation cost to the health care facility.



3.2.2 QUALITY OF HEALTH CARE

Unsupportive environment

Interviewees expressed the need for a more supportive environment in health care settings. Most of the HIV positive women interviewed cited what they perceived to be judgmental attitudes of health care workers towards them and the reluctance of health care providers to listen to their concerns. This created an environment where they did not feel comfortable to express their health concerns especially as regards their sexual health and practices. Most of the women were of the view that they are treated differently from other patients at health care sites and that they receive a lower quality of care because of their HIV positive status.

Side effects of HIV medication

Most of the HIV positive women interviewed stated that they were not adequately informed about the possible side effects of taking the HIV medication. They expressed the view that such information would have better prepared them for the side effects they experienced. While some women experienced the side effects of the medication only during the initial states of treatment, a few continued to experience negative side effects months or years later. The side effects experienced include: nausea, nightmare, vomiting, difficulty sleeping, generally feeling unwell, weakness throughout the body, and changes in body shape -increased fat in the breasts and waist.

Waiting period for medication

Many interviewees complained of the lengthy period of time they had to wait to receive their medication. They explained that they had to take time off from work to visit the health care facility for the medication and the waiting period usually exceeds that which their employers or supervisors allowed. At times, this translated into lost wages.

Waiting period for certain test results

Some of the interviewees indicated that because of their positive HIV status, they are required to have more frequent pap smears than HIV negative women who are sexually active. They expressed concern that the long delay in the receipt of the test results may have negative implications for them as they more likely to have abnormal pap smears than HIV-negative women.⁵

3.3 PRIVACY AND CONFIDENTIALITY

PRIVACY IN THE HEALTH CARE SETTING

Hospital staff not directly involved on client's treatment having access to records

Patient privacy and confidentiality were some of the major concerns of the HIV positive women who were interviewed. Many of the interviewees were of the view that hospital staff who in their view are not directly involved in their treatment such as porters, persons who schedule their appointments, take their weight etc. have access to their records. As evidence of this, some interviewees gave examples of offensive remarks and gestures made to them by hospital staff (who were not nurses or doctors), for example being called 'AIDS gal' and being pointed out in some cases by security guards working at the health care facility.

Unprofessionalism of medical staff

One of the common complaints among the interviewees is that they often encounter medical staff that are unprofessional and insensitive. Interviewees explained that some nurses when performing venepuncture 'taking blood' loudly express that they do not want any of the 'AIDS blood' to touch them. The women said that this was humiliating and they felt as if they were

⁵ **Further medical research is to be conducted on this issue.

treated differently from patients suffering from diseases for which they were viewed as being not at fault.

Inclusion of mother's HIV status on children health records

A few interviewees stated that the health records of their children contained their HIV positive status, even though the children are HIV negative. While two of these women were successful in getting this removed from their children's health records; the other two women said they did not know that they could have done something about it.

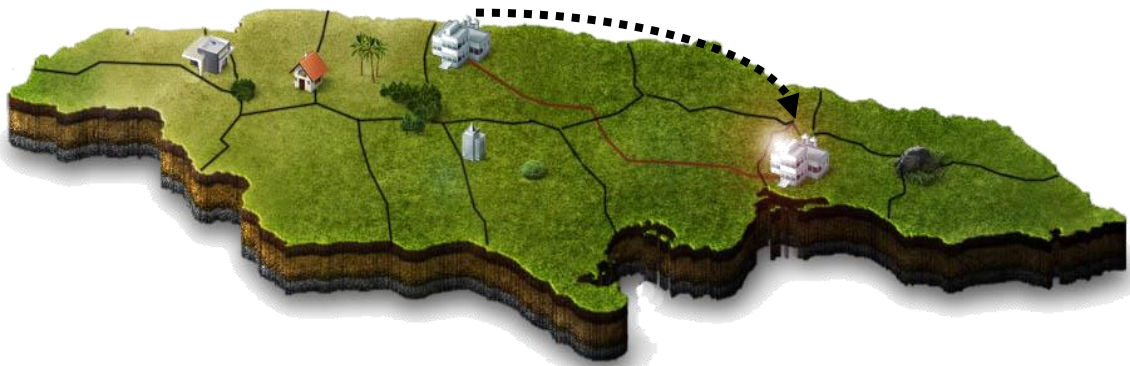
PRIVACY IN COMMUNITY AND WORKPLACE SETTINGS

One of the primary concerns of HIV positive women is the protection of their privacy. They fear that members of the community, their employers and co-workers will find out about their HIV status. Many women have found innovative means of securing their privacy. Some of these methods carry significant financial and emotional costs. Strategies adopted to help secure one's privacy include:

a) Visiting health care facilities and support centres outside one's parish or that is far away from one's community

Visiting a health care facility outside of one's parish or far away from one's community significantly reduces the chance of one's HIV status being disclosed to members of one's community and to one's employer and co-workers. This was the conclusion of the interviewees. The women explained that members of their community often visit the nearest health care facility for their own health care or work at that facility as security guards, porters, cleaning staff, nurses etc. The women fear that these persons may somehow find out about their HIV status and then disclose that information to members of the community. Four women were of the view that persons working at health care facilities (which they had visited for health care) who lived in their communities had disclosed their HIV status to the other members of the community.

Some interviewees from rural Jamaica stated that they travelled to Kingston and Saint Andrew for health care and to visit HIV care and support organizations.



Visiting a health care facility outside of one's parish or far away from one's community significantly reduces the chance of one's HIV status being disclosed to members of one's community and to one's employer and co-workers.

b) Accessing private health care

Some of the women who were diagnosed with HIV before HIV medication was offered free of cost to HIV positive persons, stated that they had sought treatment and care at private health care facilities even though it was more expensive than accessing health care at state-run facilities. The women explained that at the private health care facilities it was less likely that they would see community members, co-workers or other persons whom they did not want to suspect their HIV status. They also held the view that their medical records were kept confidential at the private health care facilities, whereas their records were exposed to a wide range of persons at the state-run health care facilities. With respect to treatment of opportunistic infections, most of the women stated that they prefer to visit private health care facilities. On many occasions, they delayed seeking treatment until they could afford to attend the private health care facility.

Increase cost of trying to secure one's privacy

The innovative means employed by HIV positive women to secure their privacy allows them to feel a greater sense of control over the way in which their HIV positive status affects their lives. However, they carry significant financial and emotional costs. These include:

- a) direct financial costs such as increased transportation costs
- b) loss of wages due to prolonged absence from work in order to get to and from the health care facilities which are further away from their home
- c) emotional strain as employing these innovative means served as a constant reminder of their HIV status and there is this constant fear that their status may be disclosed

3.4 STIGMA AND DISCRIMINATION

***Some HIV
positive women
are considered to
be dirty and
“vectors of the
disease.”***



Stigma and discrimination undermines an effective HIV/AIDS response.⁶ This is widely acknowledged. HIV positive women who shared experiences of discrimination further stated that they are presumed to be promiscuous and deserving of being infected. They are also considered to be dirty and ‘vectors of the disease’.

INTERNAL STIGMA

While the interviewees provided many examples of discrimination with respect to women infected and affected by HIV/AIDS and were able to identify ways in which it weakened HIV prevention, treatment, care and support efforts, it was evident by the end of all the interviews conducted that internal stigma (though not expressly identified by the HIV positive women interviewed) also significantly undermined HIV treatment, care and support.

⁶ See The UN Commission on Human Rights in its resolution 2003/47, UNGASS Declaration of Commitment Adopted by the General Assembly: S-26/2, 27 June, 2001

Internal stigma has been described as ‘personal shame associated with HIV/AIDS and the fear of being discriminated against on account of the illness...it is the product of the internalization of shame, blame, hopelessness, guilt and fear of discrimination associated with being HIV-positive.’ It is intrinsically linked with discrimination, as the fear of judgment or discrimination from others can profoundly influence the way in which people living with HIV view themselves and cope with their HIV status.⁷

An overwhelming majority of the HIV positive women interviewed stated that once they were diagnosed with HIV they expected to be discriminated against if their HIV status was disclosed. The women explained that this expectation was based on:

- a) The views expressed by close friends and family that they would not associate with anyone who is HIV positive
- b) The perception that HIV positive persons are treated poorly by health care workers
- c) The belief that a person’s quality of life significantly deteriorated after a person is diagnosed with HIV
- d) Their own views about persons infected with HIV
- e) Lack of knowledge about HIV and issues related to HIV

Factors influencing internal stigma

Braurd and Willis observe that there are social and contextual factors that increase or inhibit internal stigma. Social factors include gender constructions and constructions of innocence and guilt. In regards to gender constructions, HIV-related stigma interacts with existing cultural prejudices. When women become infected with HIV or develop AIDS, their already disadvantaged status may subject them to differential treatment by society. With respect to constructions of innocence and guilt, how a person acquired HIV – through sex, rape, blood transfusions, injection drug use, medical accidents, or vertically may have an impact on the shape and form of their internal stigma.

This is evident from the research conducted as interviewees who had multiple sex partners indicated that they somehow felt deserving of being infected with HIV. One interviewee stated that she was to be blamed for being infected with HIV as she was the one who insist that her sexual partner not use a condom even though he wanted to. The sense of guilt and shame was even stronger for those women who were HIV positive and whose children acquired the infection from them.

Two of the interviewees stated that they acquired HIV as a result of sexual violence: rape. One interviewee stated that she was attacked and raped when she was fifteen years old. She was tested for HIV after she reported the incident. The other woman stated that she was raped by someone she knew. Both women explained that they are very angry and do not understand why they were raped and further why they acquired HIV. Interviewees who were married or in

⁷ Braurd and Wills 2006 “A closer look: The Internalization of Stigma related to HIV

committed relationships who acquired HIV from their partners stated that they were not deserving of HIV as they were faithful partners and were not promiscuous. They highlighted the fact that they knew of women who are involved in sex work or who have multiple sex partners and who are HIV negative even though they are categorized as a traditional high risk group for HIV/AIDS.

A supportive environment, the power relations between the woman and her partner and her living situation are contextual factors which impact the way in which she deals with or experiences internal stigma.



The environment in which HIV positive women live or operate is crucial to their response to stigma. A supportive environment, the power relations between the woman and her partner and her living situation are contextual factors which impact the way in which she deals with or experiences internal stigma (Broaurd and Wills 2006). During the interviews it was observed that the women who indicated that they had a strong support system at home spoke less of guilt and shame than the women who stated that they were repeatedly ridiculed by family members, former intimate partners and community members. One middle-aged woman shared that she is repeatedly cursed by members of her community and her children are teased about her HIV status by other children and adults in the

community. She stated that the guilt and shame she feels for having HIV and for the way her children are treated by members of the community has pushed her to the brink of suicide. She stated that with the counselling and support she is now receiving from a support organization she rarely thinks of suicide as she must be strong for her children. While she has informed her adult child of her HIV status, she lies to her younger children whenever they ask about statements by community members that she has HIV and will soon die. She

maintains that it would only add emotional strain on these children if she told them the truth which would only serve to distract them from achieving their educational goals.

Role of health care and support services providers

One key observation that was made by a support services worker is that oftentimes it is the type of counselling which support organizations provided for HIV positive women sometimes help to fuel internal stigma. The concern is that HIV positive women are told by their health care providers, support providers, counsellors etc, that they should protect themselves from discrimination by limiting disclosure of their HIV status. Women are advised to lie about their HIV status. In some instances, women start to despise themselves for lying and 'living a double life.' This sometimes triggers emotional problems, difficulty sleeping etc.

EFFECTS OF HIV RELATED STIGMA AND DISCRIMINATION

It is evident from the findings of the research conducted that there are far reaching negative effects of stigma and discrimination for HIV positive women and their families and also for the wider society. The experiences shared by the interviewees support the conclusion that in Jamaica, stigma and discrimination have far reaching negative effects. These include:

- a) Undermining of prevention efforts as some HIV positive women shared that they: (i) continued to breast feed their babies even where it is unsafe to do so. They do this to refute suspicions about their HIV positive status; (ii) continued to engage in unsafe sexual intercourse, as their insistence on condom use raises questions about their fidelity and suspicions about their health
- b) Undermine treatment, care and support efforts as for example some women refuse to keep their health care appointments for fear of being seen at certain sections of the health care facility
- c) Increase women's vulnerability to other human rights violations. Some women experienced violence, were forced to leave their homes and communities, have lost employment
- d) Encourage withdrawal, isolation and thoughts of suicide

Some of the interviewees are victims of family violence, domestic violence, sexual violence, or violence perpetrated by community members.

3.5 VIOLENCE

It is generally acknowledged that violence is a cause and a consequence of HIV/AIDS. The Commission on Human Rights in its Resolution 2004/46 emphasized that violence against women and girls, including rape, incest, violence related to commercial sexual exploitation and economic exploitation as well as other forms of sexual violence, increase their vulnerability to HIV/AIDS. The Commission also stated that HIV infection further increases women's vulnerability to violence, and that violence against women contributes to the conditions fostering the spread of HIV/AIDS.⁸

For HIV positive women in Jamaica, the experience of and the threat of violence are legitimate concerns. Some of the interviewees are victims of family violence, domestic violence, sexual violence, or violence perpetrated by community members.

SEXUAL VIOLENCE

Two of the interviewees stated that they acquired HIV as a result of being raped. This revelation must be read together with a recent World Bank study which found that Jamaica has a rape rate which is higher than the global average. While the worldwide average for rape was 15 per 100,000, Jamaica has an average of 51 per 100,000.⁹



⁸ The Commission on Human Rights Resolution 2004/46 of 20 April 2004

FAMILY VIOLENCE, DOMESTICE VIOLENCE AND COMMUNITY VIOLENCE

A few interviewees disclosed that they were physically and emotionally abused by family members who know or suspect that they are HIV positive. This was especially so for the women who were dependent on family members for financial support and accommodation. Some of the women said that they often feel deserving of the violence meted to them as they had brought shame to the family. Two women had left their community because of persistent threats of violence against them due to their HIV status. Many interviewees explained that the threat and fear of violence discourage them from disclosing their HIV status to current and former sexual partners, family members and persons within the community.

VIOLENT RESPONSE BY CHILDREN

It was also revealed during the interviews that children who were being teased about their mother's HIV status often displayed aggression and violent behaviour towards the persons teasing them. This was particularly worrying for the mothers whose children according to them were not characteristically aggressive or violent.

3.6 ACCESS TO INFORMATION

Before they were diagnosed with HIV, some women thought it was possible for them to tell if a person was infected with HIV by looking closely at them.



HIV-RELATED INFORMATION

What was clear from the interviews conducted was that HIV positive women in Jamaica do not have adequate access to accurate information regarding those issues relating to HIV. This was especially so with respect to information regarding their sexual and reproductive health.

Interviewees pointed to their own lack of knowledge about HIV/AIDS when they found out that they were HIV positive. Most of the women stated that initially they viewed HIV as a death sentence and were not aware of the treatment and care services available for HIV positive women. Others stated that there are health care workers who at present do not have accurate information about HIV/AIDS. A few of the older women interviewed shared that they were advised and in some cases pressured to have a tubal ligation when they were diagnosed with HIV. Some of the women heeded to the pressure even though they had never given birth. These women expressed anger and regret as they feel as if they were robbed of the opportunity to become a biological mother.

The interviewees shared some of the misconceptions they had about HIV/AIDS before they were properly informed by support

⁹ *Crime, Violence, and Development: Trends, Costs, and Policy Options in the Caribbean*, Report No. 37820 (March 2007)

organizations and by health care workers. Some believed that a woman would not acquire HIV if: she was having unprotected sex with only one partner; she rarely had unprotected sex or she was not promiscuous. Some women also stated that until they were diagnosed with HIV, they thought it was possible for them to tell if a person was infected with HIV by looking closely at them.

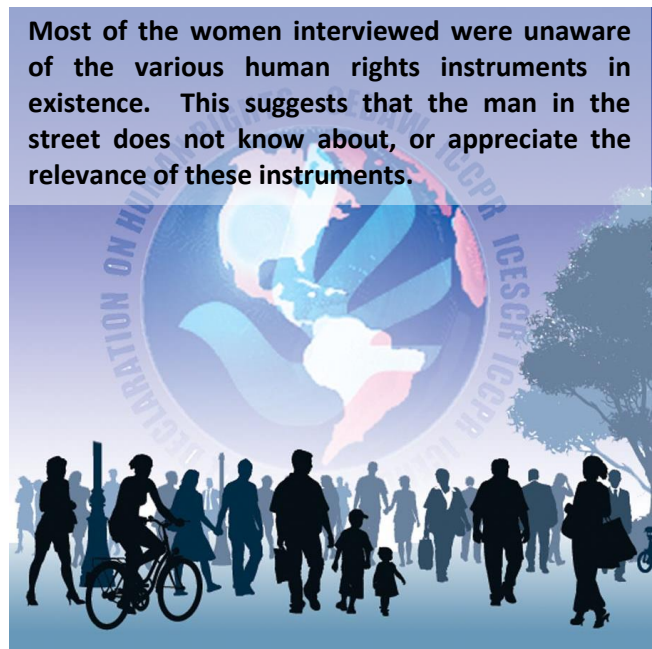
Interviewees pointed to the need for a more aggressive approach towards informing the general public about issues surrounding HIV/AIDS. While interviewees acknowledged that there has been some gains in the media efforts, they all expressed the view that the way in which the messages were being broadcasted helped to contribute to and reinforce certain stereotypes and misconceptions about HIV/AIDS. One example of this is where the television broadcasts tend to portray provocatively dressed women as being at risk of HIV infection. They stated that a more appropriate and effective approach is to use persons dressed as lawyers, doctors, teachers, politicians etc. to get the message across that everyone is at risk for HIV/AIDS and not just women in short skirts or men hanging around the streets.

Interviewees pointed to the need for a more aggressive approach towards informing the general public about issues surrounding HIV/AIDS. They believe that persons dressed as lawyers, doctors, teachers and politicians would be an effective way to convey the message that everyone is at risk for HIV/AIDS and not just women in short skirts or men hanging around the streets.

Information about international and regional human rights instruments and Jamaica's commitments and obligations under them

While the support services providers were aware of the relevant regional and human rights instruments and Jamaica's obligations under them, an overwhelming majority of the HIV positive women interviewed were not aware of these human rights instruments. This strongly suggests that while academics, policy makers and some support services providers appreciate the significance of Jamaica's commitments under these instruments, the wider citizenry does not know about or appreciate their relevance.

Most of the women interviewed were unaware of the various human rights instruments in existence. This suggests that the man in the street does not know about, or appreciate the relevance of these instruments.



3.7 SEXUAL AND REPRODUCTIVE RIGHTS

With respect to the observance and protection of the sexual and reproductive rights of HIV positive women in Jamaica, the research findings largely support an observation made at the *ECLAC/CDCC/CIDA/UNIFEM/CARICOM Fourth Caribbean Ministerial Conference on Women: Review and Appraisal of the Platform for Action* meeting that within the Caribbean women lack autonomy to make decisions about their own bodies, the sexuality and their fertility, including the right to a safe sex life.¹⁰

THE RIGHT TO HAVE A CHILD

Most of the interviewees who are of child-bearing age stated that they wanted to have children or have more children but were being discouraged by health care workers from doing so. A few of the older women who were at child-bearing age when they were diagnosed with HIV shared that they were at that time advised and in some cases pressured to have a tubal ligation. Some of them heeded to the pressure to have the tubal ligation done even though they had never given birth. These women expressed anger and regret as they feel as if they were robbed of the opportunity to become a biological mother. For one woman, her tubal ligation was done in the early 2000s.

¹⁰ See, Report of the ECLAC/CDCC/CIDA/UNIFEM/CARICOM Fourth Caribbean Ministerial Conference on Women: Review and Appraisal of the Platform for Action (12 – 13 February 2004); Kingstown, St. Vincent and the Grenadines

A recently diagnosed young woman (around 20 years of age) discovered her HIV status during the latter months of her pregnancy. She stated that within seconds after she gave birth, she was being advised by nurses in a manner which she describes as intimidatory, that she should immediately have a tubal ligation to prevent future pregnancies. She stated that while she was not aware of the issues surrounding pregnancy and HIV, she decided not to take the nurses' advice because of the manner in which they were speaking to her. While on the hospital bed, she called her mother via cellular phone and informed her of the nurses' advice. She was informed by her mother that she did not have to have the procedure done as it is still possible for her to give birth to an HIV-negative child in the future.



One interviewee was pleased to learn that it is possible for her to give birth to an HIV negative child.

NEGOTIATING SAFER SEX

One recurring concern of the women interviewed was the difficulty they had in negotiating safe sex with their sexual partners. While a few stated that it was they who decided when and how sexual intercourse took place, the majority of women stated that it was a challenge to convince their sexual partners to use a condom especially where condom use was not a part of their sexual relationship before they were diagnosed. This was so for women who had disclosed their HIV status to their sexual partner and especially so for women who had not disclosed their HIV status to their partners.



Majority of women stated that it was a challenge to convince their sexual partners to use a condom especially where condom use was not a part of their sexual relationship before they were diagnosed.

The challenge is not less difficult where both partners are HIV positive. Four of the interviewees stated that their partners were also HIV positive. Two of these interviewees said that safe sex was not a regular practice. Although they were aware of the risks of reinfection, they reasoned that they were both already infected so reinfection was not a big deal. They also indicated a preference for sex without the use of a condom. These interviewees did not appear to appreciate that reinfection of HIV may make treatment more difficult or less effective.

SOCIETAL NORMS REGARDING CHILD-REARING

A few of the women who were already mothers stated that they were not prepared to have more children. They cited health issues and financial constraints as the main reasons. Some of these women shared that they were being pressured by their current partner to have another child. Where the current partner is not the biological father of the woman's other children, there was the expectation that she should give birth to his biological child. The women explained that it was almost an unspoken rule that a woman of child-bearing age who is in a long term relationship with a man should carry his child. The strategy employed by the women is to focus on their poor financial conditions as the reason for delay in having another child.

INFORMATION ABOUT AND TREATMENT FOR GYNECOLOGICAL CONDITIONS

The women expressed the need for more information about gynecological conditions or vaginal infections that may affect them or that may be more difficult to treat because of their HIV status.

3.8 WORK /EMPLOYMENT

3.9 ARBITRARY DISMISSAL

Most of the interviewees were unemployed. Three HIV positive women stated that they lost their jobs after their employer discovered their HIV status. The reason reportedly given by one employer was that the woman posed a risk to his business as he may lose customers and other employees will not be comfortable working with her. Another interviewee explained that her former employer suspected that she was HIV positive because of her deteriorating health and her prolonged absence from work to seek treatment. She was dismissed because she was no longer able to effectively carry out her job. The other interviewee who was previously employed as a domestic worker shared that her employer suspected that she was HIV positive and took her to a doctor to have an HIV test done. The interviewee explained that her HIV test results was given to her employer by the medical doctor. When the results of the test confirmed her suspicions, the employer informed the other family members of her HIV status. Her employment continued for a couple months after the disclosure was made. During this time there was a marked difference in the way she was treated by the employer; she was given specific instructions not to use the kitchenware for her personal use and was told to wash the bathroom with bleach after every use. The employer soon dismissed her for poor job performance.

Three HIV positive women report that they lost their jobs after their employer discovered their HIV status.



3.9 EQUAL PROTECTION OF THE LAW

In assessing the human rights issues confronted by HIV positive women in Jamaica, attention must be paid to whether HIV positive women are afforded equal protection of the law. It is evident from the information gathered from the interviews conducted that the human rights of HIV positive women in Jamaica are being violated.

A careful examination of Jamaica's implementation of international and regional human rights conventions and of local laws, reveal that there is a disjunctive approach in the laws and policies which relate to HIV positive women. The legal framework in place to protect the human rights of

HIV positive women in Jamaica is inadequate. There is an invisibility of HIV positive women in Jamaica's domestic laws. One example of this is with respect to protecting HIV positive women from violence. There are two options available for a woman who is a victim of violence to seek relief under the law. She may turn to domestic violence legislation and to the criminal law.

Under the domestic violence legislation, for a woman to seek relief it is required that she is the spouse or former spouse of the respondent, that she is in a visiting relationship with him or that she is a member of the respondent's household. This therefore means that an HIV positive woman who is subjected to violence by other persons such as family members who do not live with her, former sexual partners with whom she did not cohabit or members of her community, cannot rely on the domestic violence legislation for protection.

The next option available to her is to seek recourse through the criminal law. This is an unattractive option as there is a higher threshold for proving that a criminal offence took place. There is also a greater threat to her privacy and personal security. If her HIV status is disclosed during the legal proceedings, there is the real risk of increased stigma and discrimination. Although she initiated the process, she may fail to continue with the legal proceedings.



4. COMPOUNDED VULNERABILITIES TO HUMAN RIGHTS VIOLATIONS EXPERIENCED BY HIV POSITIVE WOMEN

4.1 COMPOUNDED VULNERABILITIES

The research revealed that there are compounded vulnerabilities affecting HIV positive women in Jamaica which exacerbate the human rights violations they experience. These vulnerabilities vary depending on the age and socio-economic status of women infected and affected by HIV/AIDS.

One of the biggest concerns of the women was their poor economic conditions. While a few of the interviewees indicated that they had well-paying jobs and had made significant educational gains, majority of the women interviewed were unemployed. Most of these unemployed HIV positive women did not complete secondary education and have not received any special skills training that would make them competitive in the job search. For the older HIV positive women who were unemployed, their previous employment was in low skilled, low income jobs. The unemployed women who were over forty years of age were of the view that it was more challenging for them to secure employment because of their age. The women pointed out that without the requisite educational background and skills, there are little employment options available to them and they have no alternative but to rely on

men, family members and support organizations for financial support.

Some interviewees revealed that they often had sex with different men for money as many times this is the only means by which they are able to feed themselves and their children. This was so particularly among the younger women (under thirty-five years of age). They also revealed that in these circumstances it is not always possible to insist on condom use.

One of the biggest concerns of the women was their poor economic conditions. While a few of the interviewees indicated that they had well paying jobs and had made significant educational gains, majority of the women interviewed were unemployed.

It is clear from the experiences shared by the women, that poverty increases the risk of HIV transmission to other members of the society and further make fertile the ground for other human rights abuses such as violence and disregard for sexual and reproductive rights. As emphasized by the

interviewees, HIV positive women in Jamaica need to be empowered not merely by having information about HIV/AIDS and related issues but by having legal and safe means to become financially independent.

To reduce the compounded vulnerabilities of HIV positive women, state and non-state actors must understand the realities of HIV positive women in Jamaica and make a concerted effort to effectively address their needs.

4.2 SEX WORKERS

Sex workers have long been the target of HIV intervention programmes. HIV positive women who engage in sex work are at risk for increased human rights violation as there is the stigma associated with the type of work they engage in. They are also more vulnerable to violence and sexual abuse by their clients and former clients if their positive HIV status is disclosed. They also face the problem of inadequate protection from the law since the activities surrounding their work are generally criminalized and sex workers are traditionally viewed as being deserving of violence and sexual exploitation.

While some of the interviewees stated that they often engaged in sexual activities with men for money, they did not expressly identify themselves as being involved in sex work. One sex worker was interviewed. She was HIV negative. She spoke of the challenges involved in the sex industry. She explained that it is very difficult to convince men to use condoms. Therefore female sex workers who insist on condom use are likely to lose clients and profits since a significant percentage of men prefer unprotected sex.

She also pointed out that sex workers are at a greater risk of violence when they engaged in sex work on the streets or at a location of the man's choice. She expressed the view that less focus needs to be put on professional sex workers as carriers of HIV/AIDS as sex workers are now more empowered and informed about their rights and safe sexual practices. The focus should be shifted to those women who while not identifying as sex workers are expressly demanding payment of money for sex and engage in sexual intercourse with multiple men for economic benefits. She explained that these women are less likely to insist on condom use as they do not want to raise suspicions of infidelity.

She pointed out the need for improved access to and better quality health care. She identified the costs of gynecological examinations as a prohibitive factor with respect to sex workers, HIV positive women and women in general who are taking charge of their sexual and reproductive health.

4.3 TRANSGENDERED PERSONS

Supporting gender equality in the context of HIV/AIDS requires that due attention be paid to the human rights violations experienced by transgendered persons who are HIV positive. The human rights violations of transgendered persons has been largely absent from the HIV/AIDS discourse in Jamaica.

One transgendered person was interviewed. She was born male but now largely identifies as female. She is HIV negative. This interview brought to the fore some of the human rights issues affecting transgendered persons.

The main issues highlighted were: (i) discrimination based on sexual orientation and gender identity;¹¹ (ii) restricted access to health care; (iii) low quality of health care; (iv) arbitrary dismissal from place of employment and (v) violence. The interviewee had experienced all of these human right violations. For the purposes of this analysis, the information on the human rights issues affecting transgendered persons serves to highlight the complexity of the human rights abuses that HIV positive transgendered persons may experience.

Health Care

The interviewee focused on the low quality of health care for transgendered persons. She explained that the health care workers whom she has visited did not understand the dynamics and health issues of transgendered persons. They were unable to make the distinction between being transgendered and being homosexual and so were not sufficiently able to address the particular health issues she was facing.

She explained that there was a need for more information about issues surrounding transgendered persons. The interviewee shared that she engaged in dangerous practices such as unsupervised taking of female hormones by abusing female oral contraceptives. She had to seek medical attention for the adverse effects that the oral contraceptives were having on her health.

The transgender who was interviewed explained that there was need for more information about issues surrounding transgendered persons. Health care workers do not understand the dynamics and health issues facing this group.



Employment

What was also emphasized by this interviewee is the importance of employment and financial security. She stated that at present she is employed and this makes her less vulnerable to some human rights abuses as she does not have to put herself in risky situations to get money.


Avoidance of intimate relationships

While the interviewee largely identifies as a woman in her mode of dress and her employer and co-workers assume that she was born female, the interviewee expressed that she was hesitant to enter into a sexual relationship with a man. She fears rejection and violence if the heterosexual men pursuing her discovers that she is transgendered.

¹¹ This issue has been addressed in the UN Committee on Human Rights in General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12), E/C.12/2000/4, 11 August 2000. The UN Human Rights Committee has also found that protection from discrimination on the basis of 'sex' in article 26 of the ICCPR, includes discrimination based on 'sexual orientation' (see, *Toonen v Australia* (CCPR/C/50/D/488/1992) 25 December 1991).



5. EMERGING STRATEGIES, FOCUSES, BEST PRACTICES THAT ADDRESS HUMAN RIGHTS VIOLATIONS



This report highlights four strategies or best practices which are being used to support gender equality and address the human rights violations of women infected or affected by HIV/AIDS. These are:

- a. gender mainstreaming;
- b. full and effective participation of women infected or affected by HIV in the national HIV/AIDS response;
- c. Nigeria's model strategic framework for HIV/AIDS (2005 – 2009); and
- d. The PWMCM tool developed by International Community of Women Living with HIV and AIDS (ICW Global).

It is recommended that each of these approaches be carefully considered and adapted to address the human rights issues confronting women infected or affected by HIV/AIDS in Jamaica.

5.1 GENDER MAINSTREAMING

It is widely acknowledged and also evident from the research conducted that gender inequality helps to fuel the HIV/AIDS epidemic and exacerbates the human rights abuses experienced by women infected or affected by HIV. Gender mainstreaming has been endorsed as a strategy for promoting equality between women and men by the Fourth World Conference on Women in Beijing in 1995 and has been adopted by the United Nations Economic and Social Council (ECOSOC) in 1997. Gender mainstreaming is promoted within the United Nations system¹² and is now being used in numerous national HIV/AIDS responses.

Gender mainstreaming is described as:

“The process of assessing the implications for women and men of any planned action, including legislation, policies and programmes, in all areas and at all levels, and as a strategy for making women's as well as men's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all

It is widely acknowledged and also evident from the research conducted that gender inequality helps to fuel the HIV/AIDS epidemic and exacerbates the human rights abuses experienced by women infected or affected by HIV.

¹² See Commission on the Status of Women, <http://www.un.org/womenwatch/daw/csw/critical.htm> <accessed November 20, 2010>

political, economic and social spheres so that women and men benefit equally and inequality is not perpetuated. The ultimate goal is to achieve gender equality.” (*United Nations Economic and Social Council (ECOSOC) agreed conclusions 1997/2*)

Jamaica’s response to the HIV/AIDS epidemic should include gender mainstreaming as one of the strategies to address gender inequality and the resulting human rights violations of women infected or affected by HIV/AIDS.

5.2 RECOGNITION AND ENFORCEMENT OF HIV POSITIVE WOMEN’S RIGHT TO FULL AND EFFECTIVE PARTICIPATION ON THE NATIONAL RESPONSE TO HIV/AIDS

One of the key developments in HIV/AIDS response globally is the understanding that women who are infected or affected by HIV/AIDS must be involved in the HIV/AIDS response. Their voices should be heard and reflected in the policies and laws which are being developed to address the human rights issues affecting them. As pointed out in a recent UNIFEM report “*Transforming the National AIDS Response: Advancing women’s leadership and participation*” (2010), the right to full and effective participation of HIV positive women in the HIV/AIDS response is recognized in many international instruments and HIV/AIDS policies and frameworks. These include the:

1. 1995 Beijing Platform for Action
2. 1994 Declaration from the Paris AIDS Summit
3. 2001 United Nation General Assembly Declaration of Commitment on HIV/AIDS
4. 1992 Twelve Statements of the International Community of Women Living with HIV/AIDS (ICW)
5. 2002 Barcelona Bill of Rights
6. 2006 Panama Declaration
7. Nairobi 2007 Call to Action
8. 2008 Women Demand Action and Accountability Now Statement

One of the key developments in HIV/AIDS response globally is the understanding that women who are infected or affected by HIV/AIDS must be involved in the HIV/AIDS response.

To ensure that women infected or affected by HIV/AIDS are involved in Jamaica’s national HIV/AIDS response, the state must effectively address those human rights issues which essentially constitute barriers to their involvement and adopt a comprehensive approach empowering these women to become agents of change.¹³ These human rights issues include:

¹³ UNIFEM, *Transforming the National AIDS Response: Advancing women’s leadership and Participation* (2010)

gender inequality, stigma and discrimination, restricted access to health care and low quality of health care, lack of access to information and violence. A concerted effort must also be made to address the disparity as regards the burden of care on women in the home and the insufficient economic resources which prevent women infected or affected with HIV in Jamaica to think beyond *bread and butter issues*.

5.3 NIGERIA’S NATIONAL STRATEGIC FRAMEWORK FOR HIV/AIDS (2005 – 2009)

Nigeria’s National Strategic Framework for HIV/AIDS (2005-2009) is one that has been hailed as providing a ‘successful template for how the relationship between gender and HIV, particularly for women and girls, can be addressed through national response mechanisms.’¹⁴ The framework benefitted from a multi-dimensional approach and employed the following strategies:

1. Creation of a Gender Technical Committee comprised of UN entities, bilateral agencies, civil society organizations focused on women and HIV, governmental agencies, and ministries among others, in the National Agency for the Control of AIDS (NACA).
2. Advocacy for the establishment of a core thematic focus area on gender
3. Provision of gender technical support, including involvement of gender experts and champions for ongoing consultation and input, for the NACA.
4. Engagement of all key stakeholders through regular briefings and updates so that the work of the gender experts can be consistently validated.;
5. Advocacy and training with members of the State Action Committees on AIDS and other stakeholders at the state level to incorporate gender equality aspects of the National Strategic Framework; and
6. Documentation of the process for replication in other settings.¹⁵

5.4 POSITIVE WOMEN MONITORING CHANGE (PWMC)

Positive Women Monitoring Change (PWMC) is an ‘advocacy and participatory monitoring tool’ developed by International Community of Women Living with HIV/AIDS (ICW Global) in 2005 and which is in ongoing use.¹⁶ The tool focuses on access to health care, sexual and reproductive health, sexual and reproductive rights, violence against women. The PWMC tool has been used in Swaziland, Lesotho, South Africa, Uganda, Namibia, Mozambique, Kenya, Tanzania and Botswana. The tool has been described as a ‘useful framework to gather, analyze and present information; to raise awareness among positive women of issues affecting their lives and

¹⁴See UNIFEM *Transforming the National AIDS Response: Advancing Women’s Leadership and Participation* (UNIFEM 2010) 19

¹⁵ See UNIFEM *Transforming the National AIDS Response: Advancing Women’s Leadership and Participation* (UNIFEM 2010) 19

¹⁶ The PWMC tool can be accessed at http://www.icw.org/files/monitoringchangetool-designed%2009%2008%20final_0.pdf

mobilize around these issues; as well as to monitor performance and hold government accountable for translating their rights in policy and practice.’¹⁷

The PWMC tool can be used:¹⁸

- As a framework for gathering, analyzing and presenting information
- To raise collective awareness among positive women of issues affecting their lives as advocacy issues, and to mobilize around these issues through community assessments and needs assessments. It also offers a structure to bring positive women together to discuss issues that are often overlooked in other forums
- To raise awareness and issues of concern among government representatives, service providers, civil society organizations
- In workshopping to help positive women priorities issues and set advocacy agendas
- For evidence gathering for advocacy
- As a check list when asking questions at a meeting
- To monitor government commitment to rights in policy and practice.
- By academics in their research
- By CSOs to monitor their own work or the work of other

It is being used in the development of ICW’s monitoring and evaluation framework and to guide advocacy plans.

Further benefits of the PWMC tool include:


- The process of developing the tool for local contexts provides an opportunity and framework for positive women to engage with policy documents
- The tool was developed ‘by and for positive women’ exemplifying a different focus for research whereby positive women are firmly at the centre of the process.
- With accompanying fact sheets and policy briefings on the issues it addresses, the tool provides direct information and learning on these issues.
- By incorporating a training curriculum, the PWMC package also can be used for building research and monitoring and evaluation skills and capacity.

¹⁷ See UNIFEM *Transforming the National AIDS Response: Advancing Women’s Leadership and Participation* (UNIFEM 2010) 28

¹⁸ See the ICW’s 2008 publication of the PWMC tool, available at http://www.icw.org/files/monitoringchangetool-designed%2009%2008%20final_0.pdf



6. RECOMMENDATIONS



Having regard to the human rights issues confronting HIV positive women in Jamaica, this report put forward actionable recommendations to effectively address these issues. These recommendations are informed by: (i) the views expressed by key informants, especially the views of the HIV positive women who were interviewed; (ii) a critical analysis of the gaps in Jamaica's policy and legal response to HIV/AIDS; and (iii) best practices and strategies from employed by key international organizations concerned with issues of gender equality, human rights and HIV/AIDS. In sum, the recommendations focus on:

- Improving the national HIV/AIDS response
- Improving the legal framework
- Strengthening state accountability
- Supporting women infected or affected by HIV/AIDS

6.1 IMPROVE THE NATIONAL HIV/AIDS RESPONSE

Adopt a rights-based approach to HIV/AIDS

- a) Adopt a rights-based approach for the national legal and policy response to HIV/AIDS especially to address the gender dimensions of HIV/AIDS
- b) Pay particular attention to the human rights violations confronting HIV positive women and address the compounded vulnerabilities of HIV positive women

Gender Mainstreaming

- a) It is widely acknowledged that gender inequality fuels the HIV/AIDS pandemic and that women are particularly vulnerable and disproportionately impacted by the disease. As evidenced by Jamaica's most recent (2010) country progress report to the United Nations General Assembly Special Session (UNGASS), the observation that most data collection, monitoring and reporting tools that are available at the national level are gender blind or at best gender neutral¹⁹ rings true for Jamaica. It is imperative that there be gender mainstreaming in Jamaica's national HIV/AIDS response.

Adopt a multi-sectoral approach in addressing the human rights issues relating to the HIV/AIDS epidemic

- a) HIV/AIDS is a human rights and a development issue. As evidenced by the research findings, the human rights issues affecting HIV positive women in Jamaica cuts across issues of health, gender, education, economic and justice and as such demands a multi-sectoral response.

¹⁹ UNIFEM, *Transforming the National AIDS Response: Advancing Women's Leadership and Participation* (UNIFEM 2010) 27

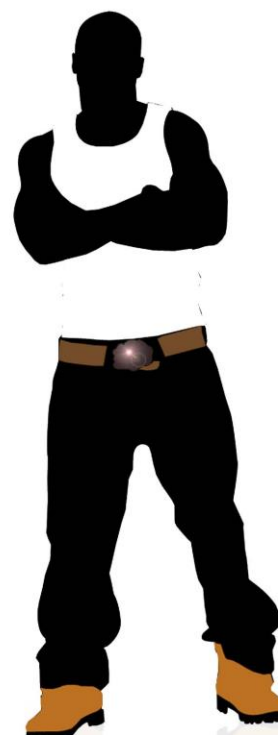
Ensure effective participation of women infected or affected by HIV/AIDS in the national HIV/AIDS response²⁰

- a) Strengthen the capacity of affected women, particularly HIV-positive women and young women, to participate fully in the HIV and AIDS response through leadership training, sustained technical support and mentorship in order to promote a new cadre of women leaders at the national level
- b) Increase women's awareness and understanding of human rights, including the right to full and meaningful participation
- c) Strengthen gender expertise within the formal decision-making bodies and funding mechanisms involved in the response to HIV and AIDS.

Educate the public about issues surrounding gender equality, HIV/AIDS and human rights

- a) Educate the public about Jamaica's commitments and obligations under the relevant regional and international human rights instruments for example, the ICCPR, ICESCR, CEDAW, CRC, Belém do Pará Convention etc.
- b) Engage in public discussions on HIV/AIDS, gender equality and human rights which do not merely focus on the traditional highlighted groups such as sex workers, men who have sex with men and injecting drug users but extend to all persons
- c) Embark on an intensive education campaign in schools at the primary and at the secondary levels with a focus on sexual behaviour, sexual health and rights
- d) Make HIV-related information readily available at community centres, pharmacies, health care facilities and at primary, secondary and tertiary level educational institutions
- e) Make clear the responsibility of the media 'to be sensitive to issues pertaining to HIV/AIDS and human rights and to reduce sensationalism in reporting',²¹
- f) Engage faith-based organizations in the discussions surrounding gender equality, HIV/AIDS and human rights

The vulnerability of men must be understood in a culture that glorifies promiscuity and bareback sex.



Men must be empowered to challenge this culture by becoming agents of change.

²⁰ Recommendation adopted from UNIFEM 2010 recommendations in *Transforming the National AIDS Response: Advancing women's leadership and participation* (UNIFEM 2010) 32

²¹ See "The Role of Media" in *Guidelines on Law, Ethics & Human Rights and HIV/AIDS*, prepared by The University of the West Indies Health Economics Unit (HEU) on behalf of The Caribbean Regional Network of People Living with HIV/AIDS (CRN+), 2007 p. 27

Involve men in the national HIV/AIDS response

- a) Understand the vulnerability of men in a culture which glorifies male promiscuity and “bareback”/unprotected sexual intercourse and which accepts aggression and violence as the accepted modes of asserting male authority; and thereafter empower men to challenge this culture by becoming agents of change.
- b) Encourage discussions among men about sexual practices, respect for women’s autonomy over their sexual and reproductive health and protecting themselves from HIV/AIDS.
- c) Encourage men who are involved with women infected or affected by HIV/AIDS to, with their partners’ permission, attend counselling sessions with them to gain a better understanding of the related issues. This was the recommendation made by a majority of the HIV positive women interviewed. They explained that the men would have a better understanding of some of the HIV related issues affecting them such as the importance of having safe sex and the dangers of breastfeeding. This would reduce the challenges they have in for example, convincing their partners to engage in safe sex and explaining the dangers of breastfeeding.

6.2 STRENGTHEN THE LEGAL FRAMEWORK IN RELATION TO HIV/AIDS

A bold approach is warranted to strengthen the legal protection for persons infected and affected by HIV/AIDS. To this end it is recommended that:

- The Constitution of Jamaica 1962, which is the supreme law of the land, be amended so as to strengthen individual rights in the Constitution and their effective enforcement within the context of protecting and supporting persons living with HIV/AIDS
- Engage in legislative reform to:
 - a. Address the invisibility of HIV positive women in the law, particularly the issue of violence against HIV positive women; and
 - b. Allow for an order of compensation to survivors of sexual violence to be considered in sentences

AMENDING THE CONSTITUTION OF JAMAICA 1962

The recommendations put forward for the amendment of the Constitution of Jamaica for the:

1. Inclusion of social and economic rights in the Bill of Rights
2. Broadening protection for civil and political rights
3. Widening protection for equality
4. Strengthening the enforcement of protective provisions
5. Allowing for international law considerations within the constitutions²²

²² These recommendations are largely influenced by those which the researcher had submitted in March 2009 for reform of the Constitution of Saint Lucia with respect to strengthening the protection for persons vulnerable to HIV and persons living with HIV/AIDS

Inclusion of social and economic rights

Right to health, right to work, right to education

Social and economic rights such as the right to health, the right to work, and the right to education are recognized as being especially important in protecting and supporting persons living with HIV/AIDS. At present, these rights are not recognized in the Constitution. It is recommended that these rights be included as enforceable rights in the Bill of Rights

Broadening protection for civil and political rights

Right to privacy

The right to privacy is inherently tied to respect for personal dignity. The importance of strengthening protection for the right to privacy cannot be overstated when one considers the serious breaches of patient confidentiality and privacy in health care and employment settings. It is recommended that the right to privacy be specifically included in the detailed section of the Bill of Rights and extended beyond its limited scope of protection from arbitrary search or entry.

Right to information

The Constitution recognizes in its freedom of expression provision, the freedom of individuals to receive and impart information without interference. This protection can be strengthened by including in the Bill of Rights a specific right to information. Equal access to HIV/AIDS treatment and care information and to sexual and reproductive health information is especially important for persons living with HIV/AIDS, as well as for persons affected and vulnerable to HIV/AIDS.

Widening protection for equality

Persons infected with HIV/AIDS face widespread discrimination in Jamaica. Although the Constitution protects against discrimination, this protection is limited to specified grounds; none of which include health status. It is recommended that: (a) the anti-discrimination provision be open-ended rather than closed so that protection against discrimination is not restricted to the grounds listed; and (b) the protection provided for in the anti-discrimination provision be extended to include discrimination on the basis of health status

Strengthening the enforcement of protective provisions

Extend the locus standi requirements

The restrictive *locus standi* requirements in the redress clause of the Constitution pose a major challenge for HIV positive persons who seek redress for breach of their fundamental rights. *Locus standi* before the court for the infringement of a right is limited to individuals who are or will be personally affected by the infringement. This strict requirement poses risks for the identity, privacy and security of persons living with HIV/AIDS who want to have their human rights enforced. The *locus standi* requirements should be extended so that persons or associations acting on behalf of others, in the interest of a class of persons, or in the public interest are

allowed to make an application to the court where there is, has been or is likely to be a contravention of one of the protected rights.

Horizontal application of the Bill of Rights

It is recommended that there be horizontal application of the Bill of Rights which would make all the protective provisions in the Bill of Rights binding on the State as well as private persons and bodies.

Enforceability of the opening section

The opening section to the Bill of Rights in Caribbean Constitutions is generally not viewed as giving rise to enforceable rights. In Jamaica, the opening section is not included in the redress clause. The position is different in Antigua and Barbuda and Belize, where the opening sections are specifically included in the redress clause. It is recommended that the opening section be included in the redress clause so that the rights mentioned therein are recognized as enforceable rights.

International law considerations within the Constitution

Adopting a rights-based approach to HIV/AIDS means that States should be held accountable for commitments made internationally, regionally and locally. It is recommended that the Constitution of Jamaica guarantees the protection of human rights set out in those international and regional conventions to which Jamaica is a State Party.²³

6.3 STRENGTHENING STATE ACCOUNTABILITY

Have mechanisms in place to hold the State accountable for violation of the human rights of HIV positive women. The suggested mechanisms are:

- a) Adopt a monitoring and evaluation framework of the State's policies and laws to assess: (i) the extent to which the State is upholding its obligations in protecting the human rights of women infected or affected by HIV/AIDS; and (ii) the extent to which the laws and policies in place translate to effective protection for women infected and affected by HIV/AIDS
- b) Establish a local body or commission to support and monitor the country's implementation of ratified (or acceded to) regional and international human rights treaties.

²³ This approach has been taken in Guyana. See article 154A of the Constitution of the Co-operative Republic of Guyana 1989 as amended by the Constitution (Amendment) (No. 2) Act 2003:10

6.4 STRENGTHEN SUPPORT FOR WOMEN INFECTED AND AFFECTED BY HIV/AIDS

Empowering women and their families to deal with the HIV-related issues which affect the family unit. This empowering can be done in the following ways:

- a) Facilitate support groups for family members of the HIV-positive women. This is especially important for children, particularly where they have become uncharacteristically aggressive, violent or withdrawn after being informed or teased about their mother's positive HIV status.
- b) Provide economic support for women infected or affected by HIV/AIDS by employing them in educational campaigns and outreach efforts. One of the concerns of some of the HIV positive women who were interviewed is that although successfully completing programs, training seminars and workshops has aided their personal development as regards the issues surrounding HIV; it should also be able to translate into some economic benefit. Some women further explained that if their economic situations are improved they are less likely to engage in risky sexual practices with men to take care of their financial needs.
- c) Improve access to adequate information with respect to issues surrounding HIV/AIDS especially as regards sexual and reproductive health and rights.
- d) Provide guidelines to HIV positive women as to the legal options available to them with respect to providing for the care and support of their children and with respect to the protection of their property rights, information as regards making a Power of Attorney and preparation of wills, including living wills.

Improve access to and the quality of health care for women infected or affected by HIV/AIDS. In order for this improvement to occur, the following critical steps must be taken:

- a) Strengthen the efforts to reach women who give birth at home with respect to HIV testing and counselling, antiretroviral therapy for pregnant women and administration of HIV prophylaxis to newborns. Protocols should be developed in these regards.
- b) Ensure training and continuous assessment of health care workers dealing with HIV positive women with a focus on stigma and discrimination in health care settings, protection of patient confidentiality and privacy and treating women and girls who are victims of sexual violence.



- c) Provide support for health care workers whereby their concerns (risks of infection, fatigue associated with dealing with HIV/AIDS cases etc;) regarding dealing with persons infected with HIV/AIDS are addressed. Improve access to, quality of and reduced costs associated with, gynecological care for HIV positive women. Concerns of the HIV positive women interviewed include the costs of pap smears and the long waiting period for the results, costs of testing for STI's and treatment of opportunistic infections.

Recognize that at present the efforts are wholly inadequate and a greater emphasis must be placed on personal responsibility.

While the efforts being employed by state and non-state actors have improved, they are wholly inadequate. Behaviour change communication is one of the primary focuses of HIV/AIDS response. However, the research conducted provided the startling revelation that HIV positive women in Jamaica who are aware of the HIV status continue to engage in unprotected sexual intercourse with persons whom are unaware of the women's HIV status. The reasons given for this practice include: (i) unavailability of condom; (ii) the need to refute suspicions of infidelity; (iii) suspicions that the sexual partner is already infected; (iv) preference for unprotected "bareback" sex; (v) protected sex serves as a reminder of one's positive HIV status; (vi) to infect others with HIV.



During the interviews some HIV positive women explained that even though they are aware of the dangers of unprotected sex and the importance of safe sex, the choice as to whether to engage in unprotected sex was a personal decision, one that is made *behind closed doors* and one that the State cannot dictate. It is therefore imperative that greater focus be placed on the responsibility of HIV positive women to comply with their prescribed treatment and care and to fulfill their responsibility to prevent exposure of HIV to other members of the society. 