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What is HIV/AIDS?

HIV (human immunodeficiency virus) was identified in 1984 as the cause of AIDS. It selectively grows in particular white cells in the blood – known as CD4+ T lymphocytes – which are essential to the body's immune response. It eventually damages or kills these cells releasing further virus to continue the spread of the infection in the body.

AIDS (**a**cquired **i**mmuno**d**eficiency **s**yndrome) is caused by HIV. By killing or damaging CD4 cells, HIV progressively destroys the body's ability to fight infections and certain cancers. People who are HIV positive are liable to infection with viruses, bacteria or yeast which do not normally harm people – so-called opportunistic infections. As the number of CD4+ T-lymphocytes decreases, the risk and severity of opportunistic illnesses increase. A person has AIDS when they have one or more of the over twenty most common opportunistic infections that define AIDS, also called "AIDS-defining illness," or if their CD4 Cell count is below 200.

HIV is found in all body fluids though it is mainly passed on through exposure to blood, semen or breast milk. This happens most commonly:

- by having unprotected sex with an infected partner. The virus can enter the body through the vagina (through sores and tears, or in some cases direct absorption through the mucus membrane), vulva, penis, rectum, or mouth during sex;
- by exposure to blood containing the virus, through sharing needles or syringes for drug use or blood transfusion;
- to babies during pregnancy, birth or breast-feeding (mother-to-child transmission).

HIV is *not* spread through casual contact such as sharing utensils, towels, or bedding or kissing, or exposure to urine, tears or sweat. The virus is not transmitted by biting insects such as mosquitoes.

There is currently no vaccine for HIV nor any medicine which will eliminate the virus from the body. The range of antiretroviral medicines available today suppress the virus and prevent AIDS from occurring or worsening.

Risk of HIV infection can be reduced by:

- not having sex with an infected person
- using a male or female condom during sex
- limiting the number of sexual partners
- not sharing needles for drug injection
- giving birth by Caesarean section if the mother is HIV positive (in conjunction with use of antiretroviral medication
- use of post-exposure medication (prophylaxis) in case of needle stick injuries to health workers or unexpected exposure such as through sexual violence.

In addition, the development of a microbicide in the near future will allow women to apply an HIV-inactivating gel prior to intercourse.

HIV is a micro-organism. AIDS is an illness. People can live with HIV with no symptoms and in excellent health.

Introduction

> **"I was living with someone who was HIV positive. When she died, then I found out… I went for a test because she did not say anything to me… At first I went a bit mad… but I decided to take the treatment because it is not the end of the world… I have learned to live with it, cope with it… I am not ashamed!"**
> 26-year-old man living with HIV/AIDS, Guyana, January 2006.

HIV/AIDS is the biggest public health challenge of our time. More than 40 million people are currently infected with HIV, the virus that causes AIDS. In the last five years, 3 million people have died each year from AIDS-related illnesses.[1]

> "…the global HIV/AIDS epidemic, through its devastating scale and impact, constitutes a global emergency and one of the most formidable challenges to human life and dignity, as well as to the effective enjoyment of human rights."
> UNGASS: Declaration of Commitment on HIV/AIDS.[2]

HIV/AIDS affects everyone in every region and the response to the pandemic is global. National responses are increasingly determined by global health initiatives and guidelines, and financed by developed countries in the North and international agencies. HIV/AIDS is primarily a disease of poverty, its spread is intricately linked to the wider inequalities of poverty and gender, and it disproportionately affects the most marginal and disempowered. The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that 90 per cent of people living with HIV/AIDS are living in the global South.[3] Once infected, people living with HIV and AIDS face further marginalization and discrimination because of the extreme stigma associated with the disease.

> **"[Before I found out that I was positive] I thought, oh! they are the walking dead."**
> Woman living with HIV/AIDS, Guyana, January 2006.

HIV/AIDS is heavily affecting the Caribbean region and its population. Only sub-Saharan Africa has a higher percentage of its population living with HIV/AIDS. According to UNAIDS, AIDS is now the leading cause of death in men and women between the ages of 15 and 44 living in the Caribbean.[4] The main mode of transmission is through heterosexual intercourse. Infection rates currently stand at an estimated 2.3 per cent. However, despite successes in some countries, the epidemics in many Caribbean countries are growing.[5] The

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[1] UNAIDS, Epidemic Update December 2005.
[2] United Nations General Assembly Twenty-sixth Special Session Doc: A/s-26/L.2, adopted Wednesday 27th June 2001, New York. Available at: http://www.ungasshiv.org/index.php/ungass/ungass/declaration_of_commitment.
[3] UNGASS Declaration of Commitment, Preamble, 2001.
[4] UNAIDS Caribbean region http://www.unaids.org/en/Regions_Countries/default.asp
[5] Bahamas, Barbados, Haiti and the Dominican Republic appear to have slowed the spread of HIV over the past years. UNAIDS Epidemic Update 2005.

total number of people living with the virus in the region is estimated to be 300,000, with 30,000 people becoming infected in 2005. [6]

This report is based on the findings of Amnesty International (AI) research into the connection between human rights violations and HIV/AIDS in two countries in the Caribbean, the Dominican Republic and Guyana. It shows how abuses of civil, cultural, economic, political and social rights increase people's risk of HIV infection. It also shows how those affected by HIV/AIDS are denied their human rights.

These findings highlight the close interrelationship between human rights and HIV/AIDS, a theme reflected in AI's recommendations which focus on the need for comprehensive rights-based approaches to HIV/AIDS in all areas of prevention, treatment, care and support.

AI believes that this is a crucial time in the fight against HIV/AIDS. Countries are scaling up efforts for universal access to prevention, treatment, care and support in an attempt to fulfil the critical international commitments in these areas.[7] At this time of increased political momentum, AI believes that it is vital to establish the relevance of respect for human rights in these initiatives and endeavours.

> Marie (not her real name), who is 17 years old, discovered that she was HIV positive when she visited hospital as part of the routine care provided to pregnant women. She was offered an HIV test and when she returned to receive the result she was told to bring her cousin with her, as she is underage. Marie was then told she was HIV positive.
>
> "I cried, we cried that day she [my cousin] stayed home from work. She did not go to work." Later in the day she phoned her boyfriend. "I told him, and he said he will phone the next morning. But I have not heard back since. Not since the day I told him." Marie's parents are separated and she was living with her mother but had to move when she got pregnant. She now lives with a cousin and she had to stop going to school. She sometimes goes and visits her father. Marie hardly sees her mother: "She is not so easy with it," said Marie.
>
> Marie had heard about HIV/AIDS before but she said: "I never take it so serious." She wants to go back to school and study to become a lawyer.

[6] UNAIDS Epidemic Update 2005, Fact Sheet Caribbean.
[7] These include the UNGASS 2001 Declaration of Commitment, the Millennium Development Goals, and the reaffirmed commitments from the 2005 UN Millennium Summit.

Background

HIV/AIDS in the Caribbean

Caribbean countries differ greatly in their culture, their political and legal systems and in the epidemiological development of HIV/AIDS. However, there are some similarities both in the human rights situation in the different countries and in the way in which the HIV/AIDS epidemics develop.

The Caribbean faces a number of human rights challenges, which interact with the HIV/AIDS epidemics in the region. Many countries have high levels of gun crime, and gender-based violence, including sexual violence.[8] Homophobia, including crimes against men who have sex with men, has also been widely reported by national and international human rights organizations. The justice system has been slow to respond to human rights violations. This has fostered a climate of impunity and a tendency in some areas for people to resort to taking the law into their own hands.

Most countries in the Caribbean are island states with small populations. This has implications for the particular dynamics of the HIV/AIDS pandemic. Migration is likely to increase as the region is moving towards greater economic integration and the Caribbean common market comes into place in 2006. Increased mobility and links between the islands increase the risk of a regional pandemic. In addition, tourism is a major source of income throughout the region and sex work, in some cases linked to the tourism industry, has been amongst the factors driving the epidemics in the Caribbean.[9]

Methodology

An Amnesty International (AI) delegation visited Guyana and the Dominican Republic at the end of 2005 and in early 2006, spending close to one month in each country. The purpose of the visits was to research the links between HIV/AIDS and human rights.

AI collected the testimonies of more than 50 people living with HIV/AIDS in rural and urban communities in both countries. In Guyana, AI visited Georgetown, Best, and Region 8, its capital Mahdia, and the communities of Campbelltown, Princeville and Micobie. In both countries the visits were made in collaboration with local organizations working in the communities. In the Dominican Republic, AI visited three *bateyes* (communities set up for workers on the sugar cane plantations) and two rural communities, one near Sabana Grande de Boyá and the other near Santiago Rodríguez. In addition to the testimonies, AI conducted six focus group interviews with more than 200 people in the different communities. AI

[8] UK Department for International Development (DFID), Regional Assistance Plan Caribbean 2004. Available at: http://www.dfid.gov.uk/pubs/files/rapcaribbean.pdf.

[9] In Guyana, infection rates in sex workers were estimated to be close to 50 per cent. WHO, Epidemiological Fact Sheet Guyana 2004 Update, Geneva, 2004. Available at: http://www.who.int/3by5/support/EFS2004_guy.pdf.

interviewed more than 50 people in the towns of Santo Domingo, Boca Chica, Puerto Plata and La Romana.

AI also interviewed a range of policy makers, people involved in setting up HIV/AIDS programmes, donors and activists in each country. AI interviewed organizations based in the United Kingdom (UK) working on the issue in the Dominican Republic and Guyana. Phone interviews were conducted with representatives of organizations working on the Caribbean.

AI's methodology and report were reviewed by an external advisory committee and the initial findings were discussed in a consultation meeting with all people interviewed in each country in early 2006.

Stigma and discrimination

> **"Nobody knows that I'm HIV positive – I haven't even told my best friend."**
> Woman in her 30s, outside Georgetown, Guyana, January 2006.

People living with HIV/AIDS have to deal not only with the disease itself, but also with society's response to it and to them. All too often that response is characterized by fear, stigma and discrimination.

> "Stigmatization occurs because of misinformation about transmission, fears of infection and the incurability of the disease, and its nature and degree are determined by a variety of social, cultural, political and economic factors, including the stage of the disease and the sex of the infected person."
> The UN Rapporteur on violence against women, its causes and consequences.[10]

The consequences of stigma and discrimination for people affected by HIV/AIDS can be very far reaching.

> "Not only are incidences of stigma and discrimination upsetting to the individual affected and may cause serious problems wherever they occur, but stigma and discrimination in health care settings can have particularly severe consequences. Fear of being identified as vulnerable to infection or as HIV-positive prevents many people from coming forward for voluntary testing, with the result that they are less likely to adopt measures to protect themselves and others from the virus. Inappropriate behavior towards those who are ill can lead to depression, social isolation and a worsening of their condition, which in turn places a greater burden on those who care

[10] UN Special Rapporteur on violence against women, its causes and consequences, Dr. Yakin Ertuek, report to the UN Commission on Human Rights, para 55, UN Doc. E/CN.4/2005/72.

> for them. Furthermore, international conventions agree that discrimination against people with HIV/AIDS is often also an abuse of their human rights."[11]

AI interviewed a wide range of people from policymakers, to activists to community members in rural areas. All without exception highlighted stigma and discrimination as obstacles to an effective response to HIV/AIDS. The stigma affects people in a whole variety of ways; it may discourage people from seeking information on prevention, as well as testing, counselling and treatment. Stigma and discrimination also influence sexual behaviour; for example they often reduce people's willingness to obtain and use condoms, for fear of being perceived to engage in risky sexual behaviour, including sex work or male sexual intercourse.

Social stigma and discrimination based on sexual orientation and gender identity is common in many parts of the Caribbean, in some cases resulting in violent attacks, some of them fatal, against people perceived to be lesbian, gay, bisexual or transgender.[12] While the vast majority – 75 per cent -- of HIV transmission is through heterosexual sex,[13] UNAIDS estimates that 12 per cent of all infections in the region are through male to male sexual intercourse.[14] Sexual intercourse between consenting male adults is illegal in some countries in the region, including Barbados, Cuba, Guyana, Jamaica and Saint Lucia. Sexual taboos and the criminalization of male homosexuality tend to drive the epidemic among men who have sex with men underground and make it harder for HIV/AIDS prevention and treatment programmes to reach them.

Poverty

> "Ill health is both a cause and a consequence of poverty: sick people are more likely to become poor and the poor are more vulnerable to disease and disability."
> UN Special Rapporteur on the Right to Health.[15]

While some Caribbean countries are reasonably wealthy and are able to offer quality health services, economic inequalities mean that marginalized groups face significant obstacles in accessing health services even where these are widely available. This is evident in health systems across the Caribbean. Poverty is a significant problem in both the Dominican Republic and Guyana where 20 and 36 per cent of the population respectively live below the

[11] PAHO, *Stigma and Discrimination in the Health Sector*, 2003. Available at: http://www.paho.org/English/AD/FCH/AI/Stigma-e-Contents.pdf.
[12] Human Rights Watch, *Hated to Death: Homophobia, Violence and Jamaica's HIV/AIDS Epidemic.* New York, 2004. Available at: http://hrw.org/reports/2004/jamaica1104/.
[13] Global Coalition on Women and AIDS, *The Female AIDS Epidemic, Statistics 2005*. Available at http://www.unaids.org/en/GetStarted/Women.asp.
[14] UNAIDS website Caribbean. Available at: http://www.unaids.org/en/Regions_Countries/Regions/Caribbean.asp.
[15] Report of the UN Special Rapporteur on the Right to Health, Paul Hunt, submitted in accordance with UN Commission on ICESCR resolution 2002/31, UN Doc. E/CN.4/2006/58, para 45.

national poverty line.[16] Treatment for HIV/AIDS is in theory available free of charge (without direct user fees) in both countries. However, AI repeatedly heard stories from people who were unable to access treatment and care because they could not afford the travel costs to get to clinics or hospitals, or they could not afford adequate food to take the medicines with.

Poverty and the lack of economic opportunities also affect the behaviour of young women and men, increasing their risk of HIV infection. While the number of women entering the labour market has increased over the past years, many women work in the informal sector, for example as domestics, where wages are very low or may largely consist of payments in kind, making it harder for women to support themselves.[17] Throughout the Caribbean, transactional sex for economic reasons between young girls and much older men is a contributing factor in the spread of HIV/AIDS.[18]

Human rights and HIV/AIDS

There are a number of international human rights conventions and standards that are relevant to HIV/AIDS. These deal with prevention, treatment, care and support, and they guarantee and protect the rights of all people living with HIV/AIDS.

The Joint UN Programme on HIV/AIDS (UNAIDS) and the Office of the UN High Commissioner for Human Rights (UNCHR) have developed specific guidelines on HIV/AIDS and human rights, and there are a range of best practice documents developed by a variety of UN agencies, which emphasize the links between HIV/AIDS and human rights and highlight how the violations of human rights drive the epidemic.

Right to health – the international framework

> "Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.
> The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."[19]
> Constitution of the World Health Organization (WHO)

The right to health has been recognized as a universal human right since the Constitution of the WHO was adopted in 1946. Members of the WHO, including the Dominican Republic, Guyana and the USA, are bound to recognize the provisions laid out within it. The right to

[16] UK Department for International Development (DFID), Regional Assistance Plan Caribbean 2004. Available at: http://www.dfid.gov.uk/pubs/files/rapcaribbean.pdf.
[17] Human Rights Watch, *Women's Rights in Latin America and the Caribbean*, 2006. Available at http://www.hrw.org/women/overview-lac.html.
[18] UNAIDS Epidemic Update 2005, Fact Sheet Caribbean.
[19] WHO Constitution, Preamble, Geneva 1948. Available at: http://policy.who.int/cgi-bin/om_isapi.dll?hitsperheading=on&infobase=basicdoc&jump=Constitution&softpage=Document42#JUMPDEST_Constitution.

health was echoed in the Universal Declaration of Human Rights adopted in 1948,[20] and further developed in the International Covenant on Economic, Social and Cultural Rights (ICESCR) of 1966, Article 12 of which states:

> 1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
>
> 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
>
> (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
>
> (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness. [21]

The UN Committee on Economic, Social and Cultural Rights monitors states' compliance with the ICESCR. The Committee has stated that ensuring the provision of health care and equal access for all to the underlying determinants of health -- such as nutritious food and clean drinking water, basic sanitation and adequate housing and living conditions -- is part of state parties' obligation to fulfil the rights enshrined in the ICESCR.[22]

The Committee has established that in order to fulfil their obligations regarding the *right* to "prevention, treatment and control of disease" [23] states must establish "prevention and education programmes for behaviour-related health concerns such as sexually transmitted diseases, in particular HIV/AIDS, and those adversely affecting sexual and reproductive health. They must also promote "social determinants of good health, such as environmental safety, education, economic development and gender equity."[24]

The right to health has since been included in various human rights treaties and standards, including the UN Conventions on the Rights of the Child (CRC),[25] on the Elimination of All Forms of Discrimination against Women,[26] and on the Elimination of All Forms of Racial

[20] Universal Declaration of Human Rights, Article 25(1) "Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services".
[21] International Covenant on Economic, Social and Cultural Rights (ICESCR), Article 12. Available at: http://www.unhchr.ch/html/menu3/b/a_cescr.htm.
[22] ICESCR, General Comment 14 , para 11.
[23] IESCR, Article 12.2 (c).
[24] ICESCR, General Comment 14, para 16.
[25] Ibid., para 24.
[26] Ibid., para 11(1)(f).

Discrimination,[27] and in regional standards including the Additional Protocol to the American Convention on Human Rights (the San Salvador Protocol).[28]

Both Guyana and the Dominican Republic are parties to these treaties and are therefore legally bound to comply with their provisions. Both have also signed political declarations from international conferences, such as:

- the 1994 Cairo Programme of Action[29] adopted at the International Conference on Population and Development (ICPD);
- the 1995 Beijing Declaration and Platform for Action adopted at the Fourth World Conference on Women;[30]
- the 2001 Declaration of Commitment signed at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS).[31]

Available, accessible, acceptable and quality health care[32]

States must take steps, to the maximum of their available resources (including those through international cooperation) towards achieving progressively full realization of the right to health.

For all people who are sick to receive treatment and care, health care must be **available** to the whole population in a country. This requires that health care is not only available in particular areas, such as big cities, but that there are enough health services for the whole population.

Health services also have to be **accessible** to all. Physically, health services should be available to patients without long, arduous journeys that might further strain their health or prevent them from accessing treatment and care. Access to health care cannot be limited on the basis of discrimination or cost. All people must be able to access and receive health care, regardless of gender, ethnicity, sexual identity, poverty or other status. Where all patients have to pay a fee to see a doctor or nurse for example, this right might be limited.

Health care also needs to be **acceptable** to all patients. This includes ensuring that services are gender and culturally sensitive, and appropriate to the communities they serve. The confidentiality of patients must also be guaranteed at all times.

Health care should also be of sufficient **quality**, relevant to the local context. This means, for example, that services should be administered by properly trained staff, meet national and international standards, and incorporate safeguards that ensure patients get the best treatment and care possible.

[27] Ibid., para 5(e)(iv).
[28] Ibid., para 10.
[29] See http://www.iisd.ca/Cairo/program/p07000.html.
[30] See http://www.un.org/womenwatch/daw/beijing/platform/declar.htm.
[31] See http://www.ungasshiv.org/index.php/ungass/ungass/declaration_of_commitment.
[32] The right to health as set out in ICESCR Article 12 is defined in General Comment 14 of the CESCR as including the right to health care that is accessible, available acceptable and of sufficient quality.

Antiretroviral medicines have transformed the lives of people who can afford them or who have access to them through the health system. However, 90 per cent of all people living with HIV/AIDS live in countries where, until very recently, these drugs were not readily available through the public health care system and where the vast majority of those who need them cannot afford them. In the Caribbean region WHO and UNAIDS have estimated that 68 per cent of all those requiring these life-saving drugs are receiving them,[33] but this seemingly high percentage masks huge regional discrepancies.

> ***In the Dominican Republic, for example, only 33 per cent of those requiring treatment are estimated to be receiving it.[34]***
>
> ***Government estimates put the number of people receiving treatment in Guyana at around 50 per cent of those requiring antiretroviral treatment.[35]***

Often it is not simply medicines that are lacking or that are inaccessible. In poorer Caribbean countries with inadequate health systems there is a lack of laboratory facilities to carry out the tests that are required to determine whether a patient needs medication for HIV/AIDS and to monitor them once they have begun taking the drugs. There are also shortages of doctors and nurses to administer the drugs and see patients regularly.

Treatment regimes for people living with HIV/AIDS who are taking antiretroviral medicines are complex and patients need to take the drugs regularly and long-term. This adherence to treatment is vital to ensure that the medicines work.[36] Successful treatment programmes, such as the ones run by *Médecins sans Frontières* in Khayelitsha township in South Africa,[37] have shown the importance of formal and informal support systems to help people to continue taking their drugs daily. This is even more important in a situation where levels of discrimination are high, such as in Guyana and the Dominican Republic.

According to General Comment 14 of the UN Committee on Economic, Social and Cultural Rights, governments must create conditions in which people can protect themselves from HIV/AIDS [see quote above]. This would include, for example, preventative tools, such as male and female condoms. It should also encompass programmes to prevent mother-to-child transmission and comprehensive information and education programmes, as well as access to reproductive and sexual health services.

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[33] WHO and UNAIDS, March 2006. Available at: http://data.unaids.org/pub/PressRelease/2006/20060328-PR-3by5_en.pdf

[34] AI correspondence with DIGECITSS (Dirección General de Control de las Infecciones de Transmisión Sexual y SIDA), March 2006.

[35] AI interview with the Minister of Health, Georgetown, Guyana, November 2005.

[36] The Lancet, "Mortality of HIV-1 infected patients in the first year of antiretroviral therapy: comparison between low-income and high-income countries." Vol. 367: 817-824, 2006.

[37] WHO has published a study of this treatment programme as best practice. *Antiretroviral Therapy in Primary Health Care: Experience of the Khayelitsha Programme in South Africa – Case Study.* Geneva, 2003. Available at: http://www.who.int/hiv/pub/prev_care/en/South_Africa_E.pdf.

The UN Commission on Human Rights has emphasized "that violence against women and girls… increases their vulnerability to HIV/AIDS, that HIV infection further increases women's and girls' vulnerability to violence, and that violence against women and girls contributes to the conditions fostering the spread of HIV/AIDS". Addressing gender-based violence is therefore vital to realising the right to the social determinants that enable HIV/AIDS prevention. Governments are obliged under international law to exercise due diligence in order to prevent, investigate and punish all forms of gender-based violence against women.[38] The concept of due diligence describes the threshold of effort which a state must undertake to fulfill to protect individuals from abuses of their rights.[39] Due diligence includes, taking effective steps to prevent abuses, investigating abuses when they occur, bringing the perpetrators to justice in fair proceedings, ensuring adequate reparation, including compensation and redress; and ensuring that justice is dispensed without discrimination of any kind.

Women, rights and HIV/AIDS

Women are at greater risk of HIV/AIDS than men for both social and biological reasons. The majority of new HIV infections globally are now occurring in women. The UN has recognized this, stating that:

"women and girls are particularly vulnerable to HIV/AIDS owing not only to their biological conditions, but also to economic and social inequalities and culturally accepted gender roles which place them in a subordinate position vis-à-vis men regarding decisions related to sexual relations."[40]

In almost all areas where human rights and HIV/AIDS intersect women face greater discrimination and more violations of their rights than men.

Women may lack access to economic resources, have less opportunities of accessing education, or the formal job market, and in employment women tend to be paid less than men. Where women (and therefore their children) have less access to economic resources they frequently have to rely or depend on their male partners for the means to survive, and this dependency complicates their ability to negotiate safe-sex and condom use with their sexual partners. It also means that women may face increased pressure to have transactional or commercial sex in order to pay for food, education or housing.

[38] See Amnesty International, *Making Rights a Reality*, AI Index ACT 77/049/2004.
[39] A state "can be held complicit where it fails systematically to provide protection from private actors who deprive any person of his/her human rights." Report of the UN Special Rapporteur on violence against women, its causes and consequences, 04/01/1996, UN Doc E/CN.4/1996/53, para 32.
[40] UN Special Rapporteur on Violence against Women, its causes and consequences, Report to the UN Commission on Human Rights, E/CN.4/2004/66, para 47.

Women are more likely to know their HIV status as testing is frequently available in antenatal clinics. Often women discover they are HIV-positive when visiting a clinic or health centre before giving birth. Telling their partners about their status also carries risks. The UN Commission on Human Rights has underscored the links between women's roles, gender-based discrimination, sexual violence and the risk of HIV/AIDS.[41]

Sexual and reproductive rights

Sexual and reproductive rights are about every individual's ability to freely and responsibly make choices about questions relating to their sexual and reproductive lives. Comprehensive sexual and reproductive health services are essential to fighting HIV/AIDS.[42]

The ICESCR guarantees the right to maternal, child and reproductive health (Article 12(2)(a)). The UN Committee on Economic, Social and Cultural Rights has clarified that this must involve "measures to improve child and maternal health, sexual and reproductive health services, including access to family planning, pre- and post- natal care, emergency obstetric services and access to information, as well as to resources necessary to act on that information." The Committee has also stated that:

"States should refrain from limiting access to… contraceptives and other means of maintaining sexual and reproductive health."[43]

Right to seek, receive and impart information[44]

Information is a key tool in empowering people to make choices about their sexual and reproductive health and is therefore a vital element in preventing HIV infections. Accurate information must be both available, accessible, and in a format that is relevant to the target audience, in order to ensure it has maximum impact. For example it should be produced in formats which can be used by people who do not read or speak the national language, and not limited by stigma or taboos, or by political considerations, including those of donor states and agencies. The UN Committee on Economic, Social and Cultural Rights has stated that state parties to the CESCR should refrain "from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information".[45]

The right "to provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them" is a key component of the right to health.[46] In relation to young people, states are required to "ensure that appropriate goods, services and information for the prevention and treatment of STIs

[41] UN Commission on Human Rights Resolution 2005/41, 'Elimination of Violence against Women', UN Doc. E/CN.4/RES/2005/41, paras 10 and 12.
[42] See e.g. ICESCR General Comment 14, and CEDAW General Recommendation 24, 1999.
[43] ICESCR, General Comment 14, para 14 and 34.
[44] ICCPR, Article 19 (2), CRC 13(1).
[45] ICESCR, General Comment 14, para 34.
[46] Ibid., para 44.

(sexually transmitted infections), including HIV/AIDS, are available and accessible" to adolescents.[47]

Furthermore the UN Committee on the Rights of the Child has stated: "Education plays a critical role in providing children with relevant and appropriate information on HIV/AIDS which can contribute to a better awareness and understanding of this phenomenon and prevent negative attitudes towards victims of HIV/AIDS."[48]

Discrimination

People affected by HIV/AIDS face discrimination in many areas of their lives. Discrimination -- the systematic denial of rights to certain people because of who they are or who they are perceived to be -- is a human rights abuse which often leads to further abuses.[49]

The Committee on Economic, Social and Cultural Rights has explicitly stated that discrimination in access to health care and other factors which impact on the right to health is prohibited.[50]

In addition, the UN Commission on Human Rights has stated that:

> "discrimination on the basis of AIDS or HIV status, actual or presumed, is prohibited by existing international human rights standards, and that the term "or other status" in non-discrimination provisions in international human rights texts can be interpreted to cover health status, including HIV/AIDS."[51]

People affected by HIV/AIDS can face discrimination in health centres and clinics when they go for treatment or to get general sexual and reproductive health services. This can range from doctors refusing to perform surgery on a patient who is HIV-positive, to treatment being delayed and patients and their families being verbally abused.

As this report shows, people living with HIV/AIDS also face discrimination in the workplace. Some may lose their jobs after disclosing their status. Some employers force workers to take HIV tests, others test them without their knowledge or consent, in clear violation of human

[47]UN Committee on the Rights of the Child, General Comment No. 4 (2003) on Adolescent Health and Development, para 23.
[48] Committee on the Rights of the Child 32nd session; 13-31 January 2003; CRC/GC/2003/1.
[49] *Discrimination* has been defined as "any distinction, exclusion, restriction or preference based on [an internationally prohibited ground of discrimination] which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life." [49] International Convention on the Elimination of All Forms of Racial Discrimination, Article 1(1), International Convention on the Elimination of All Forms of Discrimination Against Women, Article 1.
[50] ICESCR, General Comment 14, para18.
[51] UN Commission on Human Rights; Resolution 1995/44 U.N. Doc. E/CN.4/1995/44 http://www1.umn.edu/humanrts/UN/Resolutions95.html

rights obligations and government guidelines, which stipulate that testing should be voluntary and with full consent of the testee.[52] In some cases, people living with HIV/AIDS are unable to find work because of their status; in others, employment may be conditional on a negative HIV test. Similarly, children and adolescents might face discrimination in their access to education, based on their perceived or actual HIV status. If no mechanisms are available to allow people to challenge such discrimination then their rights are further violated by denying them access to justice.

The UN Committee on the Rights of the Child has noted that children have the right to be free from discrimination on the basis of their sexual orientation and health status (including HIV/AIDS).[53] It has also stated that states are obliged to "adopt legislation to combat practices that either increase adolescents' risk of infection or contribute to the marginalization of adolescents who are already infected with STIs or HIV."[54]

Discrimination against people based on their sexual orientation or gender identity, including men who have sex with men, manifests itself in a number of ways including the criminalization of same-sex relationships. Men who have sex with men often face additional stigma because of the incidence of HIV/AIDS in gay men and the history of the pandemic that was initially associated mainly with gay men in the global North.

Right to privacy - HIV testing

Confidentiality is of prime importance in the context of HIV/AIDS because of the stigma that surrounds the disease and the discrimination faced by people living with HIV/AIDS.

Article 17 of the International Covenant on Civil and Political Rights states that no-one "shall be subjected to arbitrary or unlawful interference with his privacy."[55]

According to the *UN Guidelines on HIV/AIDS and Human Rights* this encompasses the obligation to respect physical privacy, including the obligation to seek informed consent to HIV testing and to respect the confidentiality of all information relating to a person's HIV status.[56] The *Guidelines* also recognize the duty of states to protect this right. Often health care providers disclose the status of the patient, or systems for treatment, care and support are set up in a way that actively undermines people's right to confidentiality.[57]

[52] UN Guidelines on HIV/AIDS and Human Rights. For a full discussion of testing and human rights standards see the section on testing below.
[53] UN Committee on the Rights of the Child, General Comment No. 4 (2003) on Adolescent Health and Development, para 6(a).
[54] Ibid., para, 23(b).
[55] ICCPR, Article 17.
[56] UN Guidelines on HIV/AIDS and Human Rights, Article 97 -100. Available at: http://www.ohchr.org/english/about/publications/docs/g6.pdf.
[57] IESCR, General Comment 14, para 12c, specifically recognises that acceptability of health care includes: "All health facilities, goods and services must be respectful of medical ethics and culturally appropriate […] as well as being designed to respect confidentiality…."

Testing for HIV/AIDS is key for successful prevention, treatment, care and support. Voluntary testing with pre- and post- test counselling provides an important opportunity to educate the person about prevention and treatment. For those who test positive, this knowledge can help them avoid re-infection[58] and protect their sexual partners.

According to UN guidelines, testing should be guided by "the three C's" – confidentiality, informed consent and counselling.[59] Compulsory testing -- forcing someone to take an HIV test or testing someone against their will -- is "a violation of the right to security of person".[60]

The main model of testing followed is known as Voluntary Counselling and Testing (VCT). VCT involves a person volunteering to go for a test, and counselling before and after the test about the implications of the test result. The discussion around HIV testing and human rights is receiving new focus and attention in the context of the roll-out of antiretroviral treatment across the global South. One of the key challenges to increasing people's access to antiretrovirals is posed by the fact that VCT is only available to approximately 10 per cent of the population in the global South.[61] The result is that more and more testing is routinely offered in the public health system in settings which might lack the necessary resources. [62]

One of the easiest ways of increasing the number of people tested for HIV/AIDS is to routinely offer the test to pregnant women at ante-natal clinics. The patient has the choice to refuse a test, but there are concerns around routinely offering an HIV test in this way, including issues of informed consent. If offered routinely, as part of a pregnancy, systems need to be in place to provide sufficient counselling and explanation of the full consequences of a positive test result. There are also concerns relating to the ability of ante-natal clinics to provide the confidentiality and privacy required for HIV testing.

Participation – the role of civil society

The participation of people living with HIV/AIDS in designing and implementing responses to HIV/AIDS is a central principle of a rights-based approach. It is vital to ensure that programmes and policies are developed and implemented with the full and meaningful participation of those that they are intended to assist, and that this participation translates into genuine influence over the decisions taken, including the monitoring and follow-up of these decisions.

[58] Re-infection can occur when a person living with HIV/AIDS has unprotected sex with another person living with HIV/AIDS. As there are different strains of the virus, and HIV mutates over time, treatment becomes much more complicated and potentially impossible.
[59] UNAIDS/WHO Policy Statement on HIV Testing, 2004. Available at: http://www.unaids.org/en/Policies/Testing/default.asp.
[60] UN Guidelines on HIV/AIDS and Human Rights, Article 113.
[61] UNAIDS/WHO Policy Statement on HIV Testing, 2004.
[62] 'Special Focus; Emerging Issues in HIV/AIDS' *Health and Human Rights*, Vol. 8, No 2. 2005, Cambridge, USA.

The Committee on Economic, Social and Cultural Rights has recognized that an "important aspect is the participation of the population in all health-related decision-making at the community, national and international level" [63] and urged states to "refrain… from preventing people's participation in health-related matters."[64]

Civil society and people living with and affected by HIV/AIDS should participate in all decision-making related to HIV/AIDS at all levels. This includes meaningful participation in determining of clinical protocols, devising treatment, care and prevention programmes, in the decision-making processes of international, governmental and other bodies that design HIV/AIDS related policies, including participation in decisions on the allocation of funding. Civil society and people living with HIV/AIDS should also be included in monitoring governments' progress in the fulfilment of their commitments and obligations relating to HIV/AIDS.

International Cooperation and Assistance

States have the primary obligation to ensure the respect, protection and progressive fulfilment of human rights within their borders. International standards recognizing the right to health also set out the role of international cooperation and assistance in realizing this right.

Human rights obligations of states acting abroad include:

Respect the right to health. This includes refraining from any policy which would impede or violate the right to health of the population in any country where assistance is provided (either through governments or through other actors). For example, in the context of HIV/AIDS this would include ensuring that government policies do not promote the intellectual property rights of big businesses over the right of the population to access essential medicines.[65] This also means ensuring that policies do not amount to deliberately withholding or misrepresenting information vital to protection from HIV/AIDS; and ensuring respect for the principle of non-discrimination.

Protect the right to health from violations by other parties over whom the state exercises jurisdiction.[66] This would include exercising due diligence to ensure that pharmaceutical companies do not undermine the right of people to access essential medicines.

[63]ICESCR, General Comment 14, para 11.
[64] Ibid.,para 34.
[65] The WTO TRIPS (Trade Related Intellectual Property Rights) Agreement, for example has provisions that exempt essential medicines from WTO trade rules in specific circumstances.
[66] "States parties have to …prevent third parties from violating the right [to health] in other countries, if they are able to influence these third parties by way of legal of political means, in accordance with the Charter of the United Nations and applicable international law." UN ICESCR, General Comment No. 14, para 39.

Achieve progressively the full realization of the right to health (through facilitation, promotion and provision).[67] This includes ensuring that international assistance programmes prioritize core elements of the right to health including access to essential medicines, access to information essential to prevent HIV/AIDS, and access to the most effective means of protection.

Under the UN Charter, all member states pledge to take joint and separate action to work towards universal respect for human rights for all, without distinction.[68] This obliges all states to seek international assistance where needed and to ensure that any assistance provided complies with international human rights laws and standards. Those states in a position to offer international assistance should do so where necessary to ensure that, at the very least, minimum essential levels of the right to health are realized for all.[69]

When providing international cooperation and assistance, all governments are bound, through the WHO Constitution and other human rights instruments, to recognize the right to health as a fundamental human right and must ensure that their programmes of international assistance respect, protect and fulfil the right to the highest attainable standard of health of the population in the recipient state.

[67] "Depending on the availability of resources, States should facilitate access to essential health facilities, goods and services in other countries, wherever possible and provide the necessary aid when required." IESCR, General Comment No. 14, 39. This elaborated the conditions for these obligations which had earlier been expressed more directly in relation to the right to adequate food: "States parties should take steps to respect the enjoyment of the right to food in other countries, to protect that right, to facilitate access to food and to provide the necessary aid when required." IESCR, General Comment No. 12, para 36.

[68] UN Charter Articles 55 and 56. This is reiterated in the ICESCR, Article 2(1) and the CRC, Article 4 which bind states to take steps, individually and through international assistance and cooperation, according to the maximum of available resources towards the full realization of the rights guaranteed in those treaties, including the right to health.

[69] "[I]n accordance with Articles 55 and 56 of the Charter of the United Nations, with well-established principles of international law, and with the provisions of the Covenant itself, international cooperation for … the realization of economic, social and cultural rights **is an obligation of all states**… it is particularly incumbent on those States which are in a position to assist others in this regard." UN Committee on ESCR, General Comment No. 3 (State Obligations) 1990, para 14 (emphasis added).

Human rights and HIV/AIDS in the Dominican Republic

Living with HIV/AIDS in the Dominican Republic – Rita's story

Portrait of Rita, woman living with HIV/AIDS. ©AI

"I don't have the money or the strength to go to the capital where I might get help", says Rita who is HIV positive and seriously ill. "I hope to live to see my nine year old child grow up and get married. But when the fever, the headache and the diarrhoea hit me, I get scared and I think I am going to die. Then I loose hope".

Rita lives in a *batey* – a community for sugar plantation workers - about two hours' drive from the capital Santo Domingo. "I used to wo rk at a hotel in the city, but six years ago I became ill and had to quit. Now I am so sick most of the time that I can barely eat or drink. Eight months ago my cousin who volunteers for an HIV/AIDS NGO took me to a hospital to take the HIV test. The test was positive. I haven't told anyone in my family".

Rita is afraid of the stigma if she is open about her HIV/AIDS status. She fears the reaction of her parents, and she doesn't know if her husband will cope with it. He insists that he is completely healthy, but she suspects that he is the one that has infected her. Rita's youngest son has learned about HIV/AIDS in school, he has asked her in tears if she will die from AIDS being as ill as she is. Rita has not told him about her status as she does not want to make him unhappy.

"No treatment is available here. My husband only gets occasional jobs and sometimes he doesn't get paid. Some days my youngest children of nine and thirteen walk from house to house with a bucket and a rag washing clothes for other people in order to get a meal. Do you think that the people who work with AIDS problems can help me?".

Background

The Dominican Republic has a population of 8 million people, some 25 per cent of whom live below the national poverty line.[70] According to UNAIDS, 88,000 people --1.7 per cent of the population-- in the Dominican Republic are living with HIV/AIDS, of which it is estimated

[70] UNAIDS Epidemiological Update 2004.

that between 10-15,000 people need antiretroviral treatment. Some 2,700 people living with HIV/AIDS were receiving these medicines at the beginning of 2006.[71] The main mode of transmission of HIV is through heterosexual sex.[72]

Tourism plays an important part of the country's economy, as does money sent home by Dominicans living abroad and mineral exports.[73] The free trade manufacturing zones are also important sources of income and employment. The USA is the main export partner of the Dominican Republic; 87 per cent of all goods from the free trade zones are exported to the USA, [74]and there is a large Dominican diaspora in the USA.

Some 95 per cent of Dominicans are Roman Catholics and the influence of religion is strong.[75] Since 1982 the country has had a democratically elected government. Political power tends to be held by networks of relatively wealthy elites. This has important repercussions for the response to HIV/AIDS and challenges people face in accessing treatment and care.

The Dominican Republic has had some success in slowing the spread of HIV/AIDS. For example, the rate of infection in pregnant women in many cities appears to be falling.[76] However, although two thirds of all infections occur in men, more and more women are becoming infected. Women under age 24 are twice as likely to be HIV positive as men in the same age group.[77] This is due in part to the relationships between younger women and older men which are common. HIV/AIDS is now the leading cause of death in women of reproductive age in the Dominican Republic.[78] HIV/AIDS infection rates are also particularly high in *bateyes* which are predominately populated by Haitian migrants or Dominicans of Haitian descent.

Haitian migrants and Dominicans of Haitian decent

The Dominican Republic and Haiti share a border. More than 700,000 Dominicans of Haitian descent and Haitian migrants live in the Dominican Republic.[79] AI has received many reports of discrimination against Dominicans of Haitian descent and Haitian migrants and many NGOs based in the Dominican Republic have reported high levels of xenophobia. Haiti has the highest rate of HIV infection in the Caribbean. At the beginning of the 1990s prevalence rates were as high as 8 per cent in Haiti. These have since reduced to below 5 per cent.[80]

[71] Amnesty International Correspondence with DIGECITSS (Dirección General de Control de las Infecciones de Transmisión Sexual y SIDA), March 2006.
[72] UNAIDS Epidemic Update 2004.
[73] http://www.ciir.org/Templates/Internal.asp?nodeid=89680&int1stParentNodeID=89678.
[74] US Department of State Country Fact Sheets Dominican Republic.
[75] US Department of State, Background Note: Dominican Republic. Bureau of Western Hemisphere Affairs, May 2005 http://www.state.gov/r/pa/ei/bgn/35639.htm.
[76] UNAIDS AIDS Epidemic Update 2005, p.55.
[77] UNAIDS AIDS Epidemic Update 2005, p.54.
[78] USAID Country Profile HIV/AIDS, Dominican Republic.
[79] Amnesty International Annual Report 2006, Dominican Republic.
[80] UNAIDS Epidemic Update 2005.

Nevertheless, people involved in HIV/AIDS programmes and policy have observed that there is a tendency in some parts of Dominican society to portray HIV/AIDS as a "Haitian problem".

The *bateyes*

Many migrants from Haiti and Dominicans of Haitian descent live in *bateyes*. These communities were established by the owners of sugar plantations in the Dominican Republic for their workers (in most cases migrants from Haiti), and are located next to the sugar plantations.[81] It is estimated that around half of the Dominicans of Haitian descent in the Dominican Republic live in the more than 400 *bateyes*. Most *bateyes* have no running water or electricity.[82] While many migrants from Haiti initially settle in the *bateyes*, it is important to acknowledge these as permanent communities where people live for many generations. HIV prevalence in the *bateyes* is high. A demographic survey of the *bateyes* in 2002 found an HIV prevalence of 5 per cent[83] and NGOs working in the *bateyes* indicated to AI that rates might even be higher.

Part of the success in controlling the epidemic in the Dominican Republic has been attributed to a programme of working with commercial sex workers. Commercial sex work is reportedly widespread. In the late 1990s the Dominican Republic began implementing a "100 per cent condom" programme. Modelled on experiences in Thailand, the programme involved working with hotel and night club owners as well as sex workers in implementing a comprehensive condom programme. This appears to have yielded some success.[84]

HIV/AIDS-related stigma and discrimination pose a challenge in the Dominican Republic. The issue of discrimination appears particularly pronounced in the employment sector. The Dominican Republic has legislation relating to HIV/AIDS -- the AIDS law (*Ley 55-93 Sobre el SIDA*) -- which protects people living with HIV/AIDS from discrimination. However, AI found little evidence of complaints being brought forward under this law. One of the weaknesses of the HIV/AIDS legislation in the Dominican Republic appears to be the lack of specific sanctions for this kind of discriminatory practice.

HIV/AIDS testing in the Dominican Republic is not available without charge through the state health care system. In order to take an HIV test a person has to obtain a doctor's prescription authorizing the test, which in most cases involves paying a fee. A few NGOs provide HIV tests in user-friendly settings and without charge.

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[81] Human Rights Watch "*Illegal People": Haitians and Dominico-Haitians in the Dominican Republic*." April 2002, Vol. 14, No 1 B.
[82] Bernier, B. "Sugar Cane Slavery: Bateyes in the Dominican Republic" in *New England Journal of International and Comparative Law.*Vol. 9, No 1, 2003.
[83] USAID *República Dominicana*; *Encuesta Sociodemográfica y sobre VIH/SIDA en los Bateyes Estatales de la República Dominicana*. Dominican Republic, 2002.
[84] Population Council, *Promoting 100% Condom Use in Dominican Sex Establishments*. Horizons study, 2001. Available at: http://www.popcouncil.org/horizons/ressum/dr.html.

The Dominican Republic has a 100 per cent Prevention of Mother to Child Transmission Programme, funded through the Global Fund to Fight AIDS, TB and Malaria (GFATM). Women in the Dominican Republic are routinely offered an HIV/AIDS test when they attend ante-natal clinics in the public health sector.

The government receives a grant from the Global Fund to Fight AIDS that funds the provision of antiretroviral treatment for all those who need it. However, according to the government, by March 2006 of the 10-15,000 people who are believed to need antiretroviral treatment, only 2,700 people were receiving it.[85]

HIV/AIDS and the Inter-American Commission for Human Rights (IACHR, "the Inter-American Commission")

On February 29, 2000 the Inter-American Commission for Human Rights granted the first in a series of precautionary measures to Mr. Odir Miranda and 26 other members of the "Atlacatl Association", people living with HIV/AIDS in El Salvador. When issuing the precautionary measures in February 2000, the Inter-American Commission *"requested that the State of El Salvador provide the treatment and the antiretroviral medication necessary to prevent the death of the 27 persons in question, as well as the necessary hospital, pharmacological and nutritional care needed to strengthen their immune systems and prevent the development of infections."*[86] Following this precedent more and more people living with HIV/AIDS throughout the Central American and Caribbean regions submitted requests for precautionary measures to the Commission.

In 2002, the Inter-American Commission requested the government of the Dominican Republic to adopt precautionary measures aimed at assisting 10 petitioners; this was extended to cover a total of 119 people later in the same year. The Inter-American Commission noted in its Annual Report 2002 that the State had indicated that "*it would provide comprehensive care to the beneficiaries within four months and would supply drugs to selected patients who meet the criteria set by the National Commission on Antiretroviral Drugs* […]*in accordance with the availability of the resources allocated for 2002*." "*Despite the precautionary measures*," says Cesar Rosario, one of the first ten petitioners, "*there was huge confusion. At first the drugs were not coming, then in October [2002] we heard they were there, then some of the medication disappeared. I was lucky and got mine, but others did not. People continued to die*."

During 2001 and 2002 the Inter-American Commission granted precautionary measures on behalf of roughly 400 individuals in the Caribbean and Central American regions. Despite requests for precautionary measures, some governments failed to provide some claimants with

[85] Amnesty International correspondence DIGECITSS, March 2006.
[86] Annual Report of the Inter-American Commission on Human Rights 1999, *Precautionary measures granted or extended by the Commission*, OEA/Ser.L/V/II.106, Doc. 6 rev., April 13, 1999. Available at: http://www.cidh.org/annualrep/99eng/Table%20of%20Contents.htm

the medicines they required. While the exact numbers are not available, Richard Stern from a regional human rights organization, Agua Buena, who helped people making submissions to the IACHR said, "I think about half of the people, who received precautionary measures have died."

Despite the inconsistent implementation and follow-up of precautionary measures by governments, the IACHR's stance on the issue of antiretroviral treatment was the first step towards initiating public treatment programmes in many countries in the Americas. The government of the Dominican Republic has always maintained that it is financially unable to provide a national antiretroviral treatment programme through the state health care system, but with a grant from the Global Fund to Fight AIDS, TB and Malaria in 2004 it has now made a commitment to a universal treatment programme.

Public health care is not available without charge in the Dominican Republic and spending on public health care is only 2.2 per cent of the country's gross domestic product (GDP).[87] The public health care sector is very centralized. Health care is available either in the hospitals in major towns and cities or through the rural health posts, known as UNAPS (primary health care units) which have only limited services. In UNAPs in rural areas, including those in the *bateyes*, the turnover of staff is high; they are normally staffed by doctors on one-year internships. Nearly all tests, procedures and diseases require referral to a regional hospital. Once a referral is made there is no system of follow-up with the patient, as the doctor in the UNAP is not informed about the patient's further medical history.

Only the poorest sections of the population rely on the public health care system. According to some observers, the vast majority – an estimated 70 per cent – of people use the private health sector to access medication, including those for HIV/AIDS.

The response to HIV/AIDS in the Dominican Republic is led by the Presidential Council on HIV/AIDS – COPRESIDA – an umbrella body. It is chaired by the Minister of Health and its Director is directly appointed by the Minister of Health. COPRESIDA has membership of various relevant government bodies, civil society organizations and HIV/AIDS service providers. It is the principal recipient of funds from the Global Fund to Fight AIDS TB and Malaria in the Dominican Republic. COPRESIDA also manages a World Bank loan for HIV/AIDS. Following the presidential election in 2004, changes in the COPRESIDA leadership reportedly resulted in severe delays in the implementation of the Global Fund grant, which pays for antiretroviral treatment in the Dominican Republic.

DIGECITSS, which is located within the Ministry of Health, is responsible for overseeing the implementation of the National HIV/AIDS Strategic Plan. It is the technical agency responsible for the government HIV/AIDS services, including the national treatment programme.

[87] UNDP, Human Development Index, Dominican Republic, 2002. Available at: http://hdr.undp.org/statistics/data/hdi_rank_map.cfm.

One key concern expressed by civil society representatives is the lack of coordination among the different agencies who work on HIV/AIDS. This leads to duplication in activities and inefficiencies within the response to the epidemic. Although COPRESIDA and DIGECITSS involve NGOs, people living with HIV/AIDS, and other civil society groups, the civil society organizations interviewed by AI questioned the extent to which such participation translates into actual influence over HIV/AIDS - related policy and programmes.

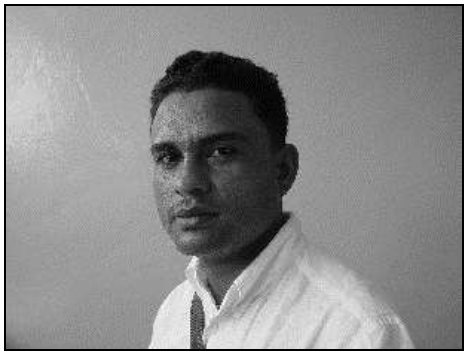
The main grant received by the Dominican Republic -- US$ 17.3 million over two years -- is from the Global Fund to Fight AIDS TB and Malaria. The government also receives a World Bank loan of US$ 25 million for its efforts in combating HIV/AIDS.

The US government is the largest bilateral donor to the Dominican Republic, providing US$ 35 million between 2002-2008 through the Conecta project, which is implemented by Family Health International. Fifty per cent of this money is given directly to the authorities to strengthen the national health system and the other half is awarded to local non-governmental organizations.[88]

Key challenges relating to HIV/AIDS

While the numbers of people accessing treatment for HIV/AIDS has rapidly increased since the introduction of the government's treatment programme, Amnesty International research in the Dominican Republic found that many people are still not receiving the medication they require. AI research suggests human rights violations occur in particular in relation to the right to health, non-discrimination, privacy and information.

Right to health



HIV activist Adonis. ©AI

Adonis, an HIV/AIDS activist working for a network of people living with HIV/AIDS in Boca Chica, described how he was told there was no treatment available for him following his positive test result in 2004. Then a doctor paid for his treatment from her own money for three months, saving his life. Only after he

[88] US funding given in the DR is conditional to the same requirements as in Guyana. See textbox on PEPFAR page 4.

approached the media making his case and concerns public was Adonis able to get treatment. Following his public criticism of the government's failure to provide the treatment he required, Adonis has reportedly received several threatening phone calls. "The brakes of my motorcycle were also messed with after I appeared on the radio denouncing the government about my lack of access to treatment," he told AI.

Adonis is now a treatment counsellor in a local health clinic. He told AI that he had just helped secure treatment for a 25-year-old woman in his community whose condition had become so critical that she had to be hospitalized, hydrated and fed intravenously to stabilize her condition. Adonis and another HIV/AIDS activist, travelled to the capital Santo Domingo and highlighted the woman's case at the COPRESIDA office. It was only following this intervention that the woman was taken to the local clinic. Adonis is looking after one of the woman's children, because there is no support available for them. Adonis said to AI: "I have seen 15 members of my community die in 2005 alone, just because they were unable to access treatment for AIDS."

Access to essential medicines

"While the government is receiving lots of funding from the donors for HIV/AIDS work and treatment, people are dying only thirty minutes away from Santo Domingo with its shiny private hospitals. In the last two years, I have seen many, many people die needlessly for lack of medicines."
A representative of a regional human rights organization, January 2006.

People living with HIV/AIDS in the Dominican Republic reportedly continue to die because they are unable to access the treatment they require, despite the national universal access to treatment plan and the increase in people accessing treatment. According to the authorities, 33 per cent of those who need antiretroviral treatment were receiving the medication in March 2006. Lack of information about where and how to access antiretroviral treatment is often a barrier to accessing medication. This is particularly the case in the *bateyes*. More than 30 people affected by HIV/AIDS interviewed by AI were unaware of the fact that effective treatment for HIV/AIDS existed and is available without charge in the state health care system.

Policy-makers, civil society representatives and medical doctors interviewed by AI said that in their work they regularly encountered people dying from AIDS for lack of medicines, either because they are unable to get onto a treatment programme, or because they do not seek medical help until they are very ill because of costs associated with obtaining a doctor's appointment.

> **"It is very difficult, it is very expensive and not really available to the people here. I inform and sensitize people, I tell them to eat well and take the vitamins, I talk to them, that is all that I can do."**
> Marisol, a health promoter, working with people living with HIV/AIDS, January 2006.

In the three *bateyes* visited by AI, researchers did not find a single person who was receiving antiretroviral treatment through the national universal access treatment plan. MUDHA (Movimiento de Mujeres Dominico-Haitianas), a local NGO, reported that of the population of around 13,000 people who they work with in 13 different *bateyes*, they only know of one person accessing antiretroviral treatment.

Access to health care

The cost of travel to an HIV/AIDS treatment centre is often a barrier to getting essential medicines. A patient needing antiretrovirals will frequently have to travel several times in order to establish whether he or she requires or is eligible for treatment.

Many of the UNAP health posts have only the most basic medicines. Some doctors and nurses interviewed by AI described having to wait between two to four months to get a supply of antibiotics. Most tests, including for HIV/AIDS, viral load and liver function tests, and all surgical procedures, have to be referred to a hospital. According to the government of the Dominican Republic, at the beginning of 2006 there was only one CD4 count machine available in the public sector. A CD4 count machine measures the amount of CD4 cells - that normally protect a person from infection - and is the most common way of determining if someone needs to take antiretroviral medicines. Once a person has started taking the drugs a CD4 count should be done regularly to monitor the medicines effectiveness.

Doctors working in the *bateyes* described their frustration at the lack of HIV/AIDS- related services that they are able to provide to their patients, and their inability to conduct follow-up. One of the health posts visited by AI had no supply of water and was lacking any sanitary facilities; neither did it have a system for keeping patient records – patient files were stored in a sink. Medical staff interviewed described similar situations in many of the major hospitals including a very irregular supply of water, electricity and basic materials such as sterile gloves, a major problem for patient care and for the safety of medical personnel. The *Colegio Médico* confirmed that the intermittent supply of electricity and safe drinking water was a problem even in the main hospitals in Santo Domingo.

AI's research suggests that treatment for HIV/AIDS is even less available in the *bateyes* than in other areas of the country. People there have very limited access to health care facilities and there are almost no HIV/AIDS- related treatment and testing facilities. Health care in the *bateyes* is generally delivered through UNAPs, which might have a full-time doctor or a doctor visiting one or two days a week, depending on the size of the community. Through funding from the Global Fund to Fight AIDS TB and Malaria, some NGOs are now providing mobile testing facilities to selected *bateyes* near the Haitian border. However, in the

communities visited by AI no testing facilities were available, and organizations surveyed said that this service had not yet been established.

Lack of transport is a serious problem for people in the *bateyes* as roads connecting these communities to the cities are particularly bad. People living with HIV/AIDS in the *bateyes*, and organizations that work with them, interviewed by AI described this as a key barrier to accessing treatment.

Right to privacy

Patient records in a health post (UNAP - primary health care unit) in a batey. ©AI

"Everyone knows [the HIV test result] before the patient -- the janitor, other patients, nurses, everyone."
A support counsellor for people living with HIV/AIDS working in a clinic in Boca Chica.

Confidentiality is a major concern in the public and private health care sector. Patients, medical staff and NGOs reported that it is common practice in many health centres and hospitals to inform the patient's family before informing the patient of a positive test result.

> **"When I went to the *colmado* [a convenience store, which also sells alcoholic beverages] everyone would say 'look, there she comes, the one with AIDS'. That's how I became suspicious that I might have AIDS."**
>
> Demaris, aged 23. She had gone to hospital when pregnant with her fourth child and received an HIV test. Demaris was told that she tested positive for a number of the tests that she took, but she was not counselled on the fact that she had tested HIV positive and the implications of it, or the links between HIV and AIDS. It was only when she returned to the hospital at a later stage that one of the doctors there explained to her what being HIV positive meant. Members of her community were aware of the result before she was.

Legislation in the Dominican Republic relating to HIV/AIDS stipulates that all information regarding a person's HIV status, testing and counselling is confidential.[89] National guidelines relating to HIV testing and counselling require informed and written consent from a patient

[89] Ley 55-93 Sobre El Sida Art. 6.

for conducting an HIV test or sharing the test results with a third party.[90] Despite this, AI received reports of several cases where people were not informed that the test was being taken, or counselled about the test result, or even told that the test result had been positive.

The *Colegio Médico*, which licenses doctors and is responsible for medical and ethical standards was established in 2001. It is estimated by the *Colegio Médico* that 20,000 doctors practising in the Dominican Republic are not yet registered with this regulatory body, making it hard to enforce and apply medical standards and protocols that have been developed, including those for HIV/AIDS treatment and testing, and PMTCT. The *Colegio Médico* described their inability to enforce these standards as a major problem in adequately addressing HIV/AIDS.

> **"The majority of members in my network have found out about their HIV status when they were looking for work, when they did not get the job, or when they were tested by their employers. Women often find out when they go to the clinic during pregnancy. Many people also found out the way I did, when they apply for US visas and have to declare their status."**
> HIV/AIDS activists, 15 November 2005.

Marisol, HIV/AIDS educator for MUDHA, working in *Batey* Basima. **©AI**

Marisol, a health promoter from a community near the town of Villa Alta Gracia, described the practice of informing patients of their test results in the presence of relatives.

> **"I went to the doctor because I was loosing weight, I was worried about my health. The doctor told me to bring my aunt. I did as I was asked, when my aunt was there with me, that's when the doctor told me I had tested positive for HIV."**
> Jorge, aged 28, Boca Chica, January 2006. He told AI that he had been unaware that he was taking an HIV test.

[90] *Normas Nacionales Para La Consejería en ITS/VIH/SIDA*. República Dominicana 2003, Serie de Normas Nacionales No. 30.

Discrimination in the workplace

Ramon, a person living with HIV/AIDS in Basima, lost his position as a worker in a fruit juice factory five years ago after his doctor sent a note to his employer disclosing his HIV status. Ramon cannot read and had not been aware that the note from his doctor disclosed his status to the employer, nor that the papers he then received from his employer marked the termination of his contract. He only discovered this when he returned with all documentation to the doctor who explained his situation and dismissal to him.

Domestic legislation prohibits dismissal in the workplace on the basis of HIV/AIDS status and making testing for HIV/AIDS a condition for employment. A report published by Human Rights Watch in 2004 documented cases where people had been dismissed following a test, or had been tested during a job application process and not been given the job, only to find out at a later stage that they were HIV positive. AI's research also revealed that women and men are sometimes tested for HIV/AIDS as part of their job application process, often without their consent and knowledge.

Sanctions are rarely applied where rights have been violated. Felicia, a 32 year old woman took her case further than most by filing an official complaint against her former employer. Felicia was working as a bus conductor in Santo Domingo when the employer reportedly asked all staff to go for a health test at a clinic. After she had been made to wait at her office for some hours, a company doctor told her that there was a problem with her test and her blood and she had to retest. At this stage she was not aware that she had received an HIV test and was told she had a blood infection. It was the company doctor and the manager jointly who told her when she got into their office about the "blood infection".

She found out that it was an HIV test when she was retested at the Red Cross clinic. She and 19 of her colleagues lost their jobs after testing positive for HIV. "When the company doctor came into the office," Felicia told AI, "he said all the people are going to die here, you need to let them go." Felicia went to the press and the Ministry of Labour, and hired a lawyer to press charges. However, she was advised by her lawyer not to press charges and she eventually accepted a settlement.

Access to information and prevention

HIV poster on road in Dominican . ©AI

Young People

> **"In school the teacher told us not to share water, not to drink from the same cup or eat from the same plate because we might get HIV or other diseases."**
> A 12-year-old girl in Basima, who is HIV positive herself.

Access to comprehensive information is a key component of successful prevention strategies in the fight against HIV/AIDS. During the course of its research in the Dominican Republic AI found limited HIV/AIDS communication materials available, especially for young people. A 2002 report by the Caribbean Group for Economic Development highlighted the early onset of sexual activity across the Caribbean, including in the Dominican Republic, and the need for comprehensive sex education from an early age,[91]as an effective means of combating early pregnancy, sexually transmitted diseases and the spread of HIV/AIDS.

In 2004, following the intervention of the Cardinal – the highest ranking member of the Catholic Church in the country -- condoms were banned in schools. Most young people interviewed by AI were receiving some limited information relating to sex and sexually transmitted diseases in schools, often through an NGO or a health promoter, but this excluded information about condoms.

In relation to the Dominican Republic, the UN Committee on the CRC in 2001 expressed, "its concern at the high teenage pregnancy […]; at the insufficient access by teenagers to reproductive health and sexual education and counselling services, including outside schools;

[91] Caribbean Group for Economic Cooperation in the Caribbean, *Youth Development in the Caribbean*. World Bank, 2002. Available at: http://www-wds.worldbank.org/servlet/WDS_IBank_Servlet?pcont=details&eid=000094946_02081004003882.

at the increasing rate of HIV/AIDS, STDs […] among children and adolescents."[92] AI spoke to several schoolchildren who believed that HIV could be transmitted through sharing water or eating utensils with a person living with HIV/AIDS. In its research AI found that the concerns raised by the Committee appear to still be relevant.

The influence of the Catholic Church is reinforced by the conditions attached to HIV/AIDS funding given by the US government. The relative emphasis on abstinence and faithfulness, especially in interventions aimed at young people, limits the number of condoms that can be purchased with the funding provided by USAID. The US funding policy also impacts on sex education and youth intervention programmes, as these cannot promote protection measures and contraceptives, despite the indication from the behavioural surveys that young women and men are sexually active and need to take necessary precautions.

There are considerable social barriers to young people, especially young girls and women, accessing condoms in the Dominican Republic. Condoms are only available either through NGOs (that are not US funded), in family planning clinics, or over the counter in pharmacies and small shops. One observer interviewed said the stigma was such that a woman would not go into a pharmacy asking for a condom as it would be assumed by others that she was a sex worker. AI interviewed a number of peer educators and young people about their condom usage and while most of them where aware of condoms and the fact that they prevented HIV transmission, they reconfirmed that women and girls would not ask for or purchase condoms. Of more than 20 women interviewed by AI, none reported seeking reproductive health services or any kind of protection before becoming pregnant.

Women in the *bateyes*

Women in the *bateyes* are particularly at risk of HIV/AIDS. They often lack access to economic resources which makes it more likely that they and their children have to rely on their husbands or partners for their income and welfare. Organizations working in these communities reported that there had been an increase in the numbers of men leaving the *bateyes* for long periods of time to take up work in other parts of the country, especially in the construction industry, while women remain at home.

Many women told AI of their inability to enforce condom use with their husbands or long-term partner for fear of jeopardising their only source of income and survival for themselves and their children. With the greater mobility and migration of men in and out of the *bateyes*, women are at increased risk of HIV/AIDS, as their husbands or long-term partner might be more likely to engage in casual sex during prolonged periods of absence from home. Where women are unable to enforce condom-use in such a situation, the fact that they have only one sexual partner or are in a long-term relationship provides no protection against HIV/AIDS.

[92] Concluding Observations of the UN Committee on the Rights of the Child, Dominican Republic, U.N. Doc. CRC/C/15/Add.150 (2001)
http://www1.umn.edu/humanrts/crc/dominicanrepublic2001.html

There are very few interventions aimed at addressing this particular situation and many of the women surveyed spoke of a need to increase work with and engage men.

Stigma around HIV/AIDS is high in the *bateyes* and misinformation persists. Many people living with HIV/AIDS interviewed by AI were not open about their HIV status with members of the community. The health posts in the *bateyes* visited by AI had no posters or information materials. Group discussions there revealed that people lacked information about treatment and were unclear about how the virus was transmitted. Some women living in the *bateyes* cannot read or may speak only Creole, limiting their ability to access information campaigns aimed at the wider population. According to one health promoter in *batey* Basima, prior to NGO involvement there had been no information available, and government representatives had not been working with the communities.

Conclusions

Despite the apparent success in lowering infection rates, in particular in pregnant women and sex workers, AI is concerned that, according to the government's own figures, nearly 70 per cent of all people requiring life-saving antiretroviral treatment in the Dominican Republic are not receiving it, despite a grant from the Global Fund to Fight AIDS, TB and Malaria to finance a comprehensive response to HIV/AIDS.

It is often the poor and marginalized who lack access to HIV/AIDS - related treatment and care because of economic and physical barriers. Where health services are available, the cost of transport to the clinic or hospital or the fee for doctors' consultations often prevent the population gaining access to necessary treatment. Many people are also denied access to information about the availability of treatment. The health services are often of poor quality; some of the health centres lack basic facilities including running water and basic medicines. Record keeping of patient records is poor or non-existent. Testing for HIV is not readily available in many areas unless provided through an NGO.

The right to privacy is often violated in relation to testing for HIV. Despite clear legal and clinical guidelines safeguarding the confidentiality of patients, this appears common practice. Where the right to privacy has been violated there is a lack of accessible mechanisms to redress individual cases.

AI found cases of discrimination against people living with HIV/AIDS in the employment sector, and cases where people had been tested by their employer without consent or as a condition of their employment. The anti-discrimination law does not appear to be providing effective redress.

Women, young people and whole communities lack access to adequate prevention, including comprehensive information, sex education and preventative tools that would allow them to protect themselves from infection. Where prevention services are provided by NGOs, provision of comprehensive information is sometimes curtailed by conditions imposed by donors.

To halt the spread of HIV/AIDS and prevent further HIV infections, the government of the Dominican Republic, and other governments that support the response to HIV/AIDS there,

need to take urgent steps to ensure that their policies and programmes respect the right to health and its underlying determinants -- including comprehensive information and barrier prevention methods -- of all people, especially women and young people.

AI found the situation, in relation to lack of treatment, access to healthcare, information and preventive tools in the *batey* communities of particular concern. The situation appears significantly worse to that in other parts of the country and suggests that the government is neglecting the population in the *bateyes*. AI found no evidence of any opportunities for residents from these communities to meaningfully participate in the development of policies and programmes aimed at fighting HIV/AIDS.

HIV/AIDS and the response to it in the Dominican Republic reflect the underlying inequalities in Dominican society. Poor and marginalized sections of society lack representation and the ability to highlight their problems and issues. Unless the rights of people are respected, protected and fulfilled, they will continue to contract an easily preventable condition and to die prematurely of a treatable one.

Recommendations on the Dominican Republic

To the COPRESIDA:

- Take immediate steps to ensure that all people in the Dominican Republic, including Haitian migrants and Dominicans of Haitian descent, have access to essential medicines for HIV/AIDS, including antiretroviral medicines and treatment for opportunistic infections, and work on developing a long-term strategy to ensure the sustainability of the HIV/AIDS treatment programme in the Dominican Republic.

- Ensure the genuine and meaningful participation of people living with HIV/AIDS and those affected by the disease, including Haitian migrants and Dominicans of Haitian descent, young people and women, in all policy, programming and funding decisions relating to HIV/AIDS, including but not limited to health sector responses.

To the government of the Dominican Republic:

Health Care

- Take steps to ensure progressively that health care is available, accessible, acceptable and of sufficient quality for the whole population, particularly young people, women, and people living in the *batey* communities, by strengthening health services.

  Availability
  - Ensure an integrated health service is developed throughout the country, prioritising those areas in most need, including rural areas and particularly the *bateyes*. The service should encompass comprehensive sexual and reproductive health services, adequate essential medicines, clean water and sanitation.
  - Progressively ensure the provision of tools for the prevention of HIV/AIDS to the whole population.
  - Immediately ensure that all testing is based on fully informed consent, includes pre- and post-test counselling, is confidential, and implemented according to the standards set out in the UN Guidelines on HIV/AIDS and Human Rights. Progressively ensure that HIV testing is available to the whole population and is linked to adequate provisions for treatment, care and support.

  Accessibility
  - Use the maximum available resources, including those through international cooperation and technical assistance to ensure that no-one is denied access to essential health services because of inability to pay; prioritize access to health care for the poor, including those living in the *bateyes*. Address barriers which can impede access to HIV prevention and care, such as costs related to

transportation, HIV testing and user-fees to see doctors, and antiretroviral medicines.

Acceptability

- Respect and protect the right to privacy in all health care settings, by guaranteeing confidentiality of HIV status, adopting and implementing clear guidelines and appropriate sanctions for violators. Ensure appropriate and confidential medical record-keeping in all health facilities.
- Promote the implementation and application of standard medical protocols and guidelines for HIV/AIDS by the medical profession, including those related to testing, PMTCT and treatment programmes, and prevention programmes in hospitals; take steps to ensure that all medical doctors are registered at the *Colegio Médico*.

Non-discrimination against people living with HIV/AIDS

- Take immediate steps to end all forms of discrimination against people living with HIV/AIDS, such as discrimination and forced testing in the employment sector, including through reform of *Ley 55-93 sobre el SIDA*, and adopt clear sanctions against private parties and companies which breach the legislation. Ensure that where people living with HIV/AIDS have experienced a violation of their rights, including through discrimination or a violation of their right to privacy, there are accessible mechanisms available to them to remedy these violations.

Non discrimination against people of Haitian descent

- Take immediate steps to end all forms of discrimination against Dominicans of Haitian descent, Haitian migrants in the Dominican Republic and against all others on the basis of their race, colour, descent, or national or ethnic origin. The Government should take urgent measures to ensure the enjoyment by persons of Haitian origin of their economic, social and cultural rights without discrimination, as stated in the Concluding observations of the UN Committee on the Elimination of Racial Discrimination (CERD/C/304/Add.74, 26 August 1999). It should further cooperate with the Committee by submitting the three (2000, 2002 and 2004) overdue reports.

Activists and civil society organizations

- Recognize the importance of work undertaken by activists and non-governmental organizations providing help and support to people living with HIV/AIDS and ensure they are free to carry out their work without fear of harassment and intimidation.

Information and education

- Ensure that all young people in the Dominican Republic have access to full, comprehensive and accessible information and prevention tools , including through introduction of comprehensive sex education in all public schools.

- Progressively ensure the availability and accessibility of comprehensive, accessible and appropriate information to the whole population, particularly young people, women, and people living in the *bateyes*.

Gender equality

- Ensure full respect of women's rights, particularly to ensure that women can protect themselves from HIV infection, and once infected have access to equal and appropriate treatment, care and support services, including by supporting the development of a female driven prevention method, exercising due diligence to prevent, investigate and punish all forms of violence against women and ensuring HIV/AIDS programming relating to women, including PMTCT programmes, reaches out to men.

International commitment to the right to health

- Recognizing the importance of the right to health, immediately ratify the Additional Protocol to the American Convention on Human Rights related to economic, social and cultural rights.

Recommendations to US government, other governments and donors

- Ensure that efforts to respond to HIV/AIDS respect, protect and fulfil human rights, particularly the right to health, and the rights of women, and the provisions outlined in the UN Charter and WHO Constitution.
- Ensure that all funding provided to support the response to HIV/AIDS in other countries does not contravene the recipient governments' obligations committed to in international human rights standards.
- Affirm commitment to the United Nations International Guidelines on HIV/AIDS and Human Rights and ensure design and implementation of responses to HIV/AIDS is in accordance with the guidance summarized in these.

HIV/AIDS and Human Rights in Guyana

Shirini – living positively in Guyana

Shirini[93] is 32, she lives outside of Georgetown and is married. She has seven daughters. "I found out I had it, I was HIV positive in 2004," she told AI, "I got it from my husband… I found out when the girl he went with came to us and said she had the HIV and I should go and take the test because she had gone with my husband." Shirini adds, "before I found out I never used the condoms. I thought my husband lived faithful and I lived faithful with him. Now we are using condoms, we get them from the clinic."

Shirini is not currently accessing antiretroviral treatment but visits the clinic Georgetown once a month for a check-up and to attend a support group. "It is not the closest [clinic] to where I live, but I am just more comfortable there."

Most of her children do not know that their parents are HIV positive, "the big ones know now, but they never really react to it." She has not told many of the people in her community. "I think people know. They hear things, but people, most people when they heard about it [HIV/AIDS] they still don't acknowledge it. People need to know that you still have a life to live."

Background

Guyana is one of the Caribbean countries most affected by HIV/AIDS. UNAIDS estimates that 2.5 per cent of the population of Guyana-- around 11,000 people -- are HIV positive[94]. Between 2,500 and 3,000 people are in need of antiretroviral treatment, the government estimates that 1,300 people receive this medication.

Guyana has a population of around 800,000, most of whom live in and around the capital, Georgetown, and in a relatively narrow strip of land along the coast.[95]

Guyana is one of the poorest countries in the region. More than 30 per cent of the population lives below the national poverty line and Guyana was the only Caribbean country to qualify for debt relief under the Highly Indebted Poor Country (HIPC) Initiative.[96]

Map of Guyana. ©Golbez

[93] Not her real name, name known to AI
[94] WHO, Epidemiological Fact Sheet Guyana 2004 Update, Geneva 2004. Available at: http://www.who.int/3by5/support/EFS2004_guy.pdf.
[95] According to the Guyana Bureau of Statistics an estimated 85.1 % are living in the coastal regions. See http://www.hiv.gov.gy/gp_hiv_gy.php#care.

The area around the capital enjoys greater relative wealth than the rest of the country. This has led to increased internal migration towards the coast and capital. There is also a steady level of migration to richer countries in the Caribbean, Europe and North America by Guyanese with skills and training. Migration into Guyana from northern Brazil and Venezuela has also increased as workers head for the gold and bauxite mines. The spread of HIV/AIDS, in particular through sex work in mining areas, is a growing concern.

The country's population is made up principally of large Indo-Guyanese and Afro-Guyanese ethnic groups and a smaller indigenous Amerindian minority. The main religions practised in Guyana are Hinduism and Christianity. Guyanese politics are largely divided along ethnic lines. The People's Progressive Party (PPP), which has been in power since 1992, has a large Indo-Guyanese following whereas the People's National Congress (PNC) has a mainly Afro-Guyanese following.

The ethnic divide in Guyana dominates national affairs and at times has prompted open conflict and violence. A 2004 report on Guyana by the UN Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and all forms of discrimination found that ethnic polarization has *"not merely distorted all aspects and forms* of "living together", but has also "perpetuated and reinforced a state of economic and social underdevelopment, to the detriment of the entire society."[97]

The government of Guyana has made the fight against HIV/AIDS a political priority. In addition, it is one of 15 countries worldwide that are a focus of the initiative launched in 2003 by US President, George W. Bush, to fight HIV/AIDS – the US President's Emergency Plan for AIDS Relief (PEPFAR).

Health care is provided without charge in the public sector. However, the health infrastructure is weak. Overall the high concentration of people in costal areas of the country is mirrored in a concentration of health care there. In contrast, in many hinterland areas only limited health care is available. Some areas of the country are more than six hours by boat or foot from the nearest health centre and are therefore serviced by a health post, which only provides basic medicines, such as pain killers. The hospitals visited by AI were basic with only limited facilities available to patients and staff.

The migration of skilled personnel, such as doctors and nurses, for better paid jobs in other Caribbean countries, Europe and North America is one of the most acute challenges faced by the public health sector and hinders the implementation and success of the HIV/AIDS treatment programme of Guyana. PEPFAR funded nine UN volunteer doctors in Guyana in 2005 to help with the treatment programme. In addition, the government has relied on an exchange programme with Cuba that provides 22 doctors to Guyana. However helpful these

[96] There are three HIPC countries in Central America, but no others in the Caribbean.
[97] Report by Special Rapporteur, E/CN.4/2004/18/Add.1, 8 January 2004.

contributions to the local health sector, the shortage of local skilled health professionals remains a problem.

In 2002 the government launched a national HIV/AIDS treatment programme. By the end of November 2005, approximately 1,300 people out of the 3,000 people requiring antiretroviral treatment were receiving it.[98]

Guyana has a Prevention of Mother to Child Transmission (PMTCT) programme and the majority of HIV testing is through this programme. The Ministry of Health estimates that currently 50 per cent of all pregnant women have access to these services; the government aims to increase this to 100 per cent as soon as possible. [99] As the majority of testing is conducted through the PMTCT programmes it is mainly women, as opposed to men, who discover their HIV positive status.

In June 2005, a trial was initiated in two ante-natal clinics whereby women were tested unless they chose to "opt out". According to official statistics 90 per cent of women at these two trial sites chose to be tested for HIV. This protocol disproportionately increases the numbers of women who test for HIV/AIDS in comparison to men, which means that the majority of people who know they are HIV positive or whose HIV status is known are women. This potentially risks HIV/AIDS being portrayed as a female disease, instead of one that affects and infects all regardless of gender. Testing women during their pregnancy means that it is the woman who reveals the HIV status in a partnership or marriage. It is women who are seen as bringing HIV/AIDS into the home, who have to disclose the status to their partner, possibly facing violence.

Guyana is currently revising its HIV/AIDS related legislation and a final draft is expected to be presented sometime in 2006. However, elections are scheduled for August 2006 and there are concerns that this could lead to a delay in passing the legislation.

There is no HIV/AIDS specific anti-discrimination legislation, but Article 149 of the Constitution protects people from discrimination by the state and its agents. The Prevention of Discrimination Act covers many aspects relating to employment and protects people from discrimination on the grounds of disability. At the time of writing, there was no known court case in Guyana relating to HIV/AIDS, or a case where a person had used the court system in Guyana to try and redress HIV/AIDS-related discrimination.

In relation to sexual violence, the Guyana Human Rights Association has raised concerns about the low rate of conviction in reported rape cases. In 2004 only 0.6 per cent of reported

[98] Interview with Minister of Health. Gender specific data about access to antiretrovirals is not available centrally for Guyana.
[99] http://www.hiv.gov.gy.

rape cases, one in 154, ended in conviction and only 3 per cent of rape cases, 20 out of 647, reported to the police between 2000 and 2004 went to court.[100]

The National AIDS Policy, which was passed by parliament in 1998, covers many of the legal aspects relating to HIV/AIDS, as well as the clinical protocols. The Policy sets out the right of people living with HIV/AIDS to access treatment and care, and it prohibits mandatory testing. It includes a section on rights and responsibilities and highlights the importance of privacy and confidentiality in the context of HIV/AIDS. However, there is no specific legislation or statue covering confidentiality of HIV status in Guyana.

The response to HIV/AIDS in Guyana is based on the 2002-2006 National Strategic Framework, as revised in 2005 and early 2006. A Presidential Commission, chaired by the President and made up of different ministries, and members of the international community, is responsible for its oversight. However, by the end of 2005 the Commission had reportedly met only once.

The Ministry of Health is responsible for the provision and oversight of public health care in the country, including the implementation of the national treatment programme and the PMTCT programme. Within the Ministry, an independent Health Sector Development Unit (HSDU) is the principal recipient of the largest HIV/AIDS-related grant received by Guyana. The National AIDS Programme Secretariat (NAPS), which is the technical agency responsible for the coordination of the response to HIV/AIDS in Guyana, also works under the auspices of the Ministry of Health. It is responsible for issues such as developing clinical guidelines, coordinating implementation and monitoring and evaluating the performance of the Ministry. The National AIDS Council is the civil society umbrella body.

Guyana's response to HIV/AIDS has received significant international attention and funding. The three major sources of funding, the Presidential Emergency Plan for AIDS Relief (PEPFAR), the World Bank and Global Fund to Fight AIDS, TB and Malaria (GFATM) have given a combined estimated total of US$ 25 million during 2005.

The US President's Emergency Plan for AIDS Relief (PEPFAR)

PEPFAR was launched in 2003 for a period of five years and with a total budget of US$ 15 billion. In 2005 the USA allocated US$ 19.4 million to Guyana through this initiative. PEPFAR funding has to be requested and approved each year by the US Congress as part of the annual budget process and is therefore linked to US domestic policy concerns and considerations. The money is spent on a variety of activities[101] and has helped finance PMTCT programmes for 5,700 women and antiretroviral treatment for 600 people living with

[100] Guyana Human Rights Association, *Without Conviction: Sexual Violence Cases in the Guyana Justice Process.* Guyana, 2005.
[101] USAID Country Profile – Guyana. Available at: http://www.usaid.gov/our_work/global_health/aids/Countries/lac/guyana.html.

HIV/AIDS in Guyana. All PEPFAR activities are directly implemented at country level through a local agency. In Guyana the local PEPFAR agent is the Guyana HIV/AIDS Reduction and Prevention Project (GHARP).

PEPFAR

PEPFAR funding has very strict conditions attached to it and organizations are monitored for their compliance with these conditions.

The majority of PEPFAR funds (46 per cent in the financial year 2005) are directed at treatment programmes, including antiretroviral treatment and treatment for opportunistic infections.[102] However, in Guyana, as elsewhere, the money provided by PEPFAR for antiretroviral treatment can only be used to purchase branded medicines, not the much cheaper generic medicines. The government of Guyana, in an effort to minimize dependence on US funds, has agreed only to purchase so-called second line treatment and medicines for children (paediatric formulae) with US funding. All other antiretrovirals are bought from generic manufacturers with funding from the Global Fund.

PEPFAR emphasizes *abstinence* and *faithfulness* over *condoms* in HIV/AIDS prevention messages and programming. A total of 33 per cent of all PEPFAR funding worldwide has to be given for programmes promoting abstinence until marriage.[103] This approach, championed by the USA, builds on a strategy known as *ABC, A= Abstinence, B= Be Faithful, C= Condom.* ABC programmes portray abstaining from sexual activity until marriage as the only acceptable behaviour for youth, where marriage is defined exclusively as heterosexual marriage in a traditional nuclear family.

These programmes are being promoted despite the fact that key studies conducted on the efficacy of these programmes by various U.S. government entities report that though abstinence only programmes can delay the age at which youth have their first sexual experiences, once they do begin, they are less prepared to take measures that would protect them from STIs, including HIV and unwanted pregnancies.[104]

The USA under PEPFAR has modified this to give a higher priority to A and B than to C. Only so-called "high risk populations" (defined as including sex workers, men who have sex with men, injecting drug users, and sexually active people living with HIV/AIDS) are targeted for condom use. Others, especially young people, are taught to abstain from sex and be faithful to a partner rather than provided with preventative tools, including condoms. In 2005 no condoms were bought with US PEPFAR funds for Guyana.[105]

[102] http://www.state.gov/documents/organization/58270.pdf
[103] Ibid.
[104] Committee on HIV Prevention Strategies in the United States, Institute of Medicine, *No Time to Lose: Getting More from HIV Prevention* (Washington, D.C.: National Academy Press, 2001), pp. 118-20.
[105] http://www.state.gov/documents/organization/58270.pdf

The obvious problem with this approach is that women may well abstain from sexual relations until marriage, be monogamous within that marriage, but because they have no ability to control their spouse's behaviour, still end up suffering from HIV/AIDS.

Organizations receiving PEPFAR funding have to explicitly oppose prostitution.[106] This prevents many organizations that work with sex workers from receiving funding, for example those organizations that work with sex workers to promote safe sex activities without directly opposing sex work. PEPFAR funds cannot be used in needle-exchange programmes, despite the fact that these have proved to be an effective way of preventing infections among drug users and their partners.[107]

President George W. Bush has reinstituted a requirement (*the Mexico City Policy)* that US funding can only go to organizations that do not support or conduct abortions, or carry out research around abortions. This ban covers organizations that provide women with information about safe abortion services or that refer them to other organizations where they might be able to access such information and services. This policy effectively excludes many sexual and reproductive health service providers from receiving funding and hinders organizations receiving US funding from providing comprehensive sex education.

Challenges relating to HIV/AIDS in Guyana

The government of Guyana is in the process of implementing a very ambitious national treatment programme that includes providing antiretroviral treatment in very remote settings. Despite this positive trend AI's research has revealed a pattern of human rights violations in particular in relation to the rights to health, non-discrimination, privacy and information.

Stigma and misconceptions

> **"I don't want them [my neighbours] to think I am one of those people."**
> A woman living with HIV/AIDS, 31 January 2006

Stigma and discrimination on the basis of a person's HIV status have many causes. They include a lack of adequate information about how the disease is spread and myths about HIV/AIDS, such as the misplaced belief that people living with HIV/AIDS somehow "deserve" it because their behaviour deviates from the perceived norm, for example sex workers and men who have sex with men.

The influence of religion on Guyanese society is an important contributing factor to the way in which HIV/AIDS is perceived and addressed. In January 2006 in an article in the local

[106] Rubinstein, L. and Friedman, E., "Human Rights and the President's AIDS Initiative" in *Human Rights Magazine*. American Bar Association, 2004. See http://www.abanet.org/irr/hr/fall04/initiative.htm.
[107] Ibid.

Stabroek News, clerics from all the major religions in Guyana stated that they would not advocate the use of condoms, even in the specific context of HIV/AIDS, because it was tantamount to condoning promiscuity and sex that is not solely for the purpose of reproduction.[108] In the same article the religious leaders also declared homosexuality a sin. This highlights not only the difficulties faced in implementing prevention programmes in Guyana, but the degree of stigma which continues to surround HIV/AIDS.

While clerics are free to express their views publicly, both as a matter of freedom of religion and conscience and of freedom of expression, Guyana's public health policy must be dictated not by religion or morality, but by science and commitment to the right to health, life and access to information.

HIV/AIDS-related stigma in the communities in the hinterland is very strong. In one community visited by AI a family hid a young girl suspected of being HIV positive to prevent her being seen or spoken to. She had been taken out of school and was ill, but according to a community leader had not been taken to see a doctor.

Despite many HIV/AIDS information campaigns in Guyana, misconceptions prevail. A 2004 survey found that 30 per cent of "out-of-school youths" reported that they thought HIV/AIDS could be transmitted through a mosquito; 22.6 per cent believed that HIV/AIDS could be transmitted by sharing a meal with an infected person; and 22.9 per cent argued people living with HIV/AIDS should be quarantined. Among workers at Guyana's main sugar company, misinformation was even more prevalent: 30 per cent believed HIV/AIDS could be transmitted by sharing a meal.[109] These misconceptions clearly feed into the stigma and fear surrounding HIV/AIDS.

Stigma is the context in which discrimination and other human rights violations against people living with HIV/AIDS has flourished. In some cases these violations in turn reinforce the stigma, resulting in a vicious cycle. The following chapters explore the impact this has had on the lives of particular groups and in particular contexts.

[108] "Where the major religions here stand on homosexuality, condoms," *Stabroek News* by O Alleyne. *Stabroek News*, 30 January 2006.
[109] Ministry of Health Guyana, Behavioural Surveillance Surveys, Executive Summary, Round 1, Volume I. Guyana, 2003/4.

Amerindian[110] population

Amerindian family in Guyana. © AI

[110] While the UN Committee on the Elimination of Racial Discrimination in their recent concluding observations on Guyana (CERD/C/GUY/CO/1421 March 2006, para.10) recommended that: "… the State party, in consultation with all indigenous communities concerned, clarify whether "Amerindians" is the preferred term of these communities," all members of the indigenous population interviewed by AI referred to themselves as Amerindians; this is reflected in the choice of language used throughout this report.

There are around 63,000 Amerindians living in Guyana. They have historically been subjected to discrimination.[111] Most Amerindians live in Regions One, Seven, Eight and Nine, the country's hinterland and mining area. These regions are relatively isolated and Amerindians tend to be excluded from the economic and political life of the country.

The gold mining industry has led to an influx of people from Guyana's coastal areas and neighbouring Brazil and Venezuela to the hinterlands. There are concerns that this migration is resulting in an increased risk of HIV/AIDS infection. Policymakers, civil society representatives and community members described a proliferation of sex work among young Amerindian girls in the towns near mining areas in Regions Seven, Eight and Nine, and there is evidence of high rates of infection among miners.[112]

Many Amerindians live in areas that are only accessible by plane, foot or boat. Electricity is limited to a couple of hours a day and there is no radio and no phone system. The majority of news and information is therefore transmitted through interpersonal communication.

In Amerindian culture there is little open debate about sex and sexuality. It is therefore vital that interventions and communication materials are tailored and engage their target audience. For example, free condoms are available at the health posts. However, some programme staff and policymakers who work with Amerindians or in areas of the hinterland, reported to AI that condoms were not widely used and Amerindians tend to distrust them, sometimes believing that they are a way of controlling the growth of their population.

At the end of 2005 Amnesty International found no evidence that HIV/AIDS-related information or communication materials are available in indigenous languages. According to the Ministry of Amerindian Affairs, HIV/AIDS information in English had been distributed in those areas where non-governmental organizations (NGOs) had visited; awareness raising activities by the government in Amerindian communities were only just beginning in 2006. AI research in a number of Amerindian communities showed that misconceptions about HIV/AIDS remained. For example, in a group discussion with women and men in Campbelltown, near the regional capital Mahdia, participants said they thought the virus was transmitted through sharing eating utensils and water.

In many communities visited by AI, health workers and community leaders described the lack of information and communication tools as a problem. The Amerindian People's Association also expressed a need for more locally appropriate information. One of the problems reported

[111] See: UN Committee on Elimination of Racial Discrimination, Press release 3 March 2006. Available at: http://www.unhchr.ch/huricane/huricane.nsf/0/8FED9490B1EDA7B9C1257129003210A4?opendocument. Amerindian People's Association of Guyana, *A Plain English Guide To the Amerindian Act*, Guyana, 1998. Available at: http://www.sdnp.org.gy/apa/topic7.htm.

[112] According to a survey conducted amongst miners in 2000. Ministry of Health, BSS Survey, Introduction, p.3. Guyana, 2000.

with the limited information materials available is that many of the images and materials lack accurate representations of Amerindians. Communication materials are often funded and developed by external donor agencies, and one of the local organizations reported that a barrier to effective prevention work was the limited opportunities for input from local people. A lack of secondary school provision in the areas where the majority of Amerindians live also means that many children do not receive education, including sex education, that imparts the life-skills which help reduce the vulnerability of young people to HIV/AIDS.

According to the National AIDS Programme Secretariat in Guyana, antiretroviral treatment and treatment for opportunistic infections relating to HIV/AIDS is almost completely unavailable in Regions One, Eight, Nine and for much of the population in Region Seven. In some of the hard to reach areas, the government plans to introduce treatment through mobile doctors in 2006.

Most rural communities have a health post with a medical worker. District hospitals, which are often two or three hours away by foot or boat, stock basic medicines such as pain killers, but reportedly only rarely dispense antibiotics or more advanced medicines. Treatment for malaria, the biggest health problem in the area, and other diseases such as tuberculosis (TB), is available only at regional hospitals which can be a long way from the villages. Health posts are not equipped to provide comprehensive sexual and reproductive health services, including testing for HIV. Testing for HIV was inaccessible to most Amerindian communities until 2005, when some testing through mobile clinics sponsored by GHARP, the local PEPFAR agent, began.

Beyond the Minister for Amerindian Affairs there is little representation of the indigenous population on any of the policy-making bodies in the response to HIV/AIDS. The Ministry of Amerindian Affairs has established an HIV/AIDS desk which began to compile a strategic plan in January 2006. However, at the time of writing, virtually all programmes and activities aimed at preventing HIV/AIDS among Amerindian communities, or at alleviating the impact of HIV/AIDS among these communities had been designed and implemented by NGOs.

Women

According to government figures, women and girls make up the majority of those under 24 living with the virus in Guyana.[113] Women, especially young women whose reproductive organs are not fully developed, are at particular risk of HIV infection. However, in addition to biological reasons, there are a number of social factors which put women at greater risk of contracting HIV.

The Constitution of Guyana prohibits discrimination on the basis of gender,[114] and more than 30 per cent of members of parliament are women.[115] However, women earn considerably less

[113] Government of Guyana, National AIDS Programme. See http://www.hiv.gov.gy/gp_hiv_gy.php#epi. March, 2006.
[114] Constitution of Guyana, Article 149, para 2.

than men.[116] UNAIDS has noted women's lack of access to economic resources affects their ability to protect themselves from HIV/AIDS. Women's economic dependence on their husbands or partners maybe one of the reasons why women feel unable to insist on the use of condoms, or negotiate fidelity and abstinence because they fear violence or reprisals that may jeopardise theirs and their children's sole source of income and survival.[117] Other factors such as religion, social and cultural obligations may also impact on women's ability to negotiate condom use, fidelity or abstinence. AI received testimonies from a number of women who had been infected by their husband or long-term partner. This highlights the need for prevention tools that women can control independently, for example microbicides.

There is limited data available about violence against women in Guyana, but the number of reports of domestic violence and gender-based violence is high. In 2004 there were 2,395 cases of domestic violence reported to the authorities and in 2005, 30 women reportedly died as a result of gender-based violence.[118] Although some steps have been taken to introduce appropriate legislation, the Guyana Human Rights Association has raised concerns about the low rate of convictions for rape charges and about the effectiveness of the legal system in addressing sexual and domestic violence.[119]

In situations of sexual violence, not only are women unable to use protective measures, but wounds resulting from violence can also increase the risk of infection through injured tissues. HIV/AIDS also puts women at increased risk of violence. The introduction of the "opt –out protocol", as described previously, in ante-natal clinics is one of the reasons that the number of women compared to men who know their HIV status has increased disproportionately. Women who test positive for HIV fear violence at the hands of their partners when they disclose their status to them. A doctor working at an ante-natal clinic reported to AI that some pregnant women who test HIV positive only return to the clinic when pregnant with a second child, having withheld the results of the test from their partners out of fear of violence.

Women's vulnerability is compounded by a reported lack of sexual and reproductive health services in Guyana, which are a key way of reaching women before they become pregnant, and providing them with information and preventative tools to protect them from HIV/AIDS. Comprehensive sexual and reproductive health services also help ensure treatment for other sexually transmitted infections, which if left untreated increase the risk of contracting HIV/AIDS. They include advice about abortion and the use of condoms and other barrier prevention measures for young people. However, organizations which provide such

[115] UNDP, Human Development Index Data, Country Factsheet Guyana. Available at: http://hdr.undp.org/statistics/data/country_fact_sheets/cty_fs_GUY.html.
[116] The estimated average female earning income in Guyana is US$ 2,426, versus an overall average of GDP per capita is US$ 4,230, this means the male to female income ratio is 0.39. Source: ibid.
[117] UNAIDS Global Coalition on Women and AIDS (2005), *Economic security for women key to HIV prevention*. Available at http://data.unaids.org/pub/BriefingNote/2006/20060308_BN_GCWA_en.pdf.
[118] Guyana Human Rights Association, *Without Conviction: Sexual Violence Cases in the Guyana Justice Process*, p. 5. Guyana, 2005.
[119] Ibid., p.5.

comprehensive sexual and reproductive health services are excluded from receiving funding from the US government. Despite the vast amount of funds available to Guyana for HIV/AIDS prevention, one leading NGO working on the provision of comprehensive sexual and reproductive health services, charges a user fee to their clients, as they allege a lack of overall funding.

Men who have sex with men

Male homosexuality is a criminal offence in Guyana.[120] In the late 1990s the HIV infection rate among men who have sex with men was estimated to be 21.2 per cent.[121] Discrimination against men who identify as gay, or men who have sex with men, is reported to be wide-spread in Guyana. There are no open cultural or social spaces where gay men, or men who have sex with men can meet openly. Representatives of lesbian, gay, bisexual and transgender (LGBT) organizations have reported that it is impossible for LGBT people to be open about their sexuality, even with friends and family.

At the onset of the HIV/AIDS epidemic, the portrayal of the disease as a "gay plague" led to a strong association between HIV/AIDS and male homosexuality. The intense discrimination against men who have sex with men reinforced the stigma attached to the disease. Similarly the fear and stigma associated with the disease has exacerbated entrenched social hostility towards LGBT people.

In 2003, during a debate to revise Article 149 of the Constitution which deals with discrimination, the Society Against Sexual Orientation Discrimination (SASOD) and other civil society organizations made an attempt to prohibit discrimination on the basis of sexual orientation, but following public protest this proposed amendment was dropped.

The criminalization of male homosexuality makes it harder to ensure that men who have sex with men have access to treatment, care and prevention programmes. One Guyanese non-governmental support organization for men who have sex with men, women who have sex with women and sex workers has not yet been able to obtain registration as an NGO, a pre-requisite for receiving funding. Fear of being perceived to be gay means that men are more likely to have sex with women in order to conceal their sexual orientation, increasing their own and their partners' risk of infection. In a 2004 survey, 84 per cent of men who have sex with men, reported that they had had sex with a woman.[122]

[120] Guyana Criminal Law Act, paras 531-533.
[121] Government of Guyana, National AIDS Programme. http://www.hiv.gov.gy/gp_hiv_gy.php?PHPSESSID=8847b264892a267cdb117ba1665f86d9#epi
[122] Ministry of Health Guyana, Behavioural Surveillance Surveys, Volume One Executive Summary. Guyana, 2004.

Discrimination in the workplace

One of the areas in which people affected by HIV/AIDS most commonly face discrimination in Guyana is in the workplace. AI received a number of reports of cases where people were allegedly dismissed by their employer following the discovery that they are HIV positive. While there is no data available on the number of cases where people have been dismissed on the basis of their HIV status, local civil society organizations and policy makers repeatedly reported that the dismissal of employees, especially in the service and hospitality sector, was common.

The majority of people living openly with HIV/AIDS whom AI questioned during its research, were working for HIV/AIDS organizations. One man living with HIV/AIDS who was working in the police force said he did not want his colleagues to know his status as he feared he would be dismissed.

A 35-year-old woman living in Georgetown who discovered she was positive in 1997 told AI that her biggest worry was not being able to provide enough food for her children. She had been unable to find work and was living on a state disability pension equivalent to US$100 per month. Many available jobs are in the food industry, but she is unable to obtain a food handling certificate because of her HIV status. She is certain she would have found employment by now were it not for her HIV status.

Despite evidence of discrimination, AI could find no evidence of formal complaints recorded in Guyana by persons who were unfairly dismissed by an employer on the basis of their HIV status. While there are some UN and government programmes in place addressing HIV/AIDS in the workplace, the evidence received by AI suggests that these fall short of adequately addressing the problem of discrimination faced by people living with HIV/AIDS. Anti-discrimination legislation in Guyana does not cover HIV/AIDS explicitly, but refers to disability. In 2004 an assessment of the law in the context of employment and HIV/AIDS, which was sponsored by the Guyana Human Rights Association, concluded that:

> "although this statute does not explicitly refer to HIV/AIDS, its prohibition of discrimination on the ground of disability combined with modern interpretations of disability ensure that persons in the public and private sector cannot refuse to hire someone on the grounds of his/her HIV status, unless such status directly impacts on the job in question."[123]

[123] Guyana National AIDS Committee, Bulkan, A., National Assessment on the Law, Ethics and Human Rights in Guyana, July 2004.

Right to health

Boat, providing main mode of transport for Micobie community in rural Guyana. © AI

Access to essential medicines varies greatly in Guyana from region to region. In addition to the Amerindians, the majority of the population in the hinterland of Guyana is unable to access medicines, unless they travel to Georgetown or have access to the regional hospitals in Regions Seven or Nine. This often involves long and expensive journeys by foot, boat, road or plane, in a country that has very limited infrastructure linking the interior to the coastal area.

For children, access to antiretroviral therapy is also limited. The government provides paediatric treatment for children living with HIV/AIDS, but acknowledges that at the end of 2005 such treatment was only available in two hospitals in the capital Georgetown. Although there are plans to extend treatment to one other hospital in Region Seven many children in Guyana will still have to travel long distances to access antiretroviral treatment.

The government provides help with travel costs from regional hospitals to Georgetown. However, for some patients the journey itself might be too arduous and may involve revealing their HIV status to people in the community. An NGO working with children orphaned or affected by HIV/AIDS reported the case of a child in Linden, a town which is a two-hour drive from the capital Georgetown, who did not access treatment because regular visits to the clinic to collect the treatment would reveal their HIV status in the community.

Once a patient begins taking antiretroviral drugs, these medicines need to be taken for life. The dosages available in Guyana mean the drugs need to be taken twice a day at a fixed time. If a patient misses a dose, the effectiveness of the drugs is significantly reduced. Ultimately if a patient does not adhere to their routine, they run the risk that their virus will become

resistant to that particular drug. The resistant strain of the virus can be passed on to another person and can reduce the treatment options of that person too.

Medical workers and policy makers interviewed by AI emphasized their concern at the number of people who were not continuing with treatment. A number of factors appear to influence the poor level of adherence to treatment. For example, some people living with HIV/AIDS choose to go to another region to receive treatment in order to protect their privacy and avoid social stigma. However, this can have a negative effect on their ability to continue treatment because of problems related to travel. It can also pose problems when they fall seriously ill as the health care provider in their home town or community may be unaware of the medicines they are taking and the possible side-effects these might have in combination with other drugs given.

At the end of 2005 only one treatment centre in Guyana was reported to have a support group for patients beginning antiretroviral treatment. Support is important to ensure patients stick to their routine and receive the help they need, but this requires a person to be open about their HIV status. In one hospital AI learned that since the beginning of the treatment programme in 2004, as many as 12 patients out of a total of 66 had discontinued their treatment; their fate was not known. Ten of the patients interviewed by AI at a treatment site said they did not want to join a support group, most of them felt there was no benefit.

Right to privacy

During its research, AI received testimonies from more than five people whose HIV status had allegedly been disclosed by doctors or medical staff to other patients or family members without their knowledge or consent. One 30-year old woman living with HIV/AIDS tested positive at a hospital outside Georgetown. She had previously been treated at another hospital in another town for Tuberculosis (TB). When she told her mother of the positive test result, her mother explained that she had known for a while, as the physician who had initially treated her for TB had tested her and revealed the test result to her mother, without informing the patient. Revealing the HIV status to family members or partners of people who have tested positive appears common. During the course of its field research AI delegates witnessed a number of incidents where the status of a person was randomly disclosed by medical staff or community members.

The implementation of proper procedures to uphold confidentiality help to protect against and prevent acts of discrimination. They also improve confidence in the provision of treatment and care. The pervasive fear of stigma and discrimination in Guyana make confidentiality of HIV status particularly important. In many cases the perception of confidentiality, or lack of it, will influence whether a person goes for an HIV test and if and where they seek treatment for an AIDS-related illness. The evidence received by AI suggests that guidelines safeguarding confidentiality of HIV status are insufficiently implemented, or inadequate to safeguard the privacy of patients.

The small size of the population of Guyana means that people accessing the health care sector are likely to meet a neighbour or relative, or are cared for by someone with ties to their family or friends. In small communities, it is also difficult to be discreet about long-distance travel to access to antiretroviral treatment at hospitals.

Other factors limiting confidentiality witnessed by AI included the use of cubicles in voluntary counselling and testing centres which allowed passers-by to overhear counselling sessions. Patients also repeatedly reported to AI that they felt that their confidentiality was compromised when collecting their medicines from the pharmacy, because they fear disclosure when requesting and collecting their medication in public.

Right to information – HIV/AIDS prevention

HIV/AIDS Awareness outside a school in Guyana. © AI

Despite an increase in HIV/AIDS-related information in Guyana, significant misconceptions about HIV/AIDS and its transmission persist. According to organizations working in the hinterland of Guyana, in many parts of the country information about HIV/AIDS is still not available, and where it is, it is provided through NGOs who may have to limit the information they give in order to comply with donor conditions.

A government survey of school students found that only 56 per cent used a condom during their first sexual intercourse,[124] suggesting the need for more HIV/AIDS information and prevention campaigns which are targeted at young people.

AI research also revealed that secondary prevention services – those aimed at people living with HIV/AIDS to ensure that they do not re-infect themselves with another strain of the virus - are limited. While most patients interviewed by Amnesty International described their experiences in accessing treatment and care as positive, the levels of awareness about treatment, side-effects and positive prevention were very limited. For example, a woman living with HIV/AIDS interviewed by AI explained that she thought the medicines meant she did not have to protect herself from re-infection or other sexually transmitted diseases. Many others interviewed also had misconceptions and queries about their treatment, indicating a need for information materials and support aimed at people living with HIV/AIDS.

AI found that in Guyana the participation of people living with and affected by the virus in HIV/AIDS programmes and policy-making was very limited. The Health Sector Development Unit and the Presidential Commission determine allocation of funds as well as policy design and strategic development. However, both lack representatives from civil society, including from members of minority groups. The National AIDS Council, the main body representing civil society, has no voice on either of these bodies. This means that campaigns and materials are often designed without the involvement and influence of the target audience. So, for example, there is a lack of appropriate materials available for the Amerindian community. Failure to meaningfully involve civil society limits the effectiveness of HIV/AIDS prevention and treatment programmes in Guyana.

International financial assistance to governments or to other organizations often has strict conditions attached, limiting the way in which it can be used. US funding, including the PEPFAR initiative, is agreed by US Congress and implemented through a locally US-established organization in the recipient country that sub-contract local civil society organizations. Beneficiaries allegedly have very limited opportunities to participate in developing the plans and priorities for the use of this funding.

Much of this funding is destined for prevention activities[125] which promote abstinence and faithfulness as opposed to condom use. These funding guidelines are in conflict with the rights to information and to health services that include sexual and reproductive health care.

[124] Ministry of Health Guyana, BSS Survey, p.52. Guyana, 2003/2004.
[125] An estimated 45% of all PEPFAR funds for Guyana are devoted to prevention activities.

This significantly limits the availability of information and tools necessary to enable people to protect themselves from HIV/AIDS.

While PEPFAR and the GHARP project have provided funding and initiated many valuable HIV/AIDS related programmes and activities, this strategy does not take account of factors such as the relatively high incidence of sexual violence in Guyana. Abstinence and faithfulness cannot provide effective protection from infection as a result of sexual violence. Similarly, a number of women interviewed by AI in Guyana had contracted HIV/AIDS within a partnership or marriage where they had been faithful. This highlights the limitation of an approach focusing on abstinence and fidelity.

Conclusions

Guyana faces significant challenges in adequately addressing its HIV/AIDS epidemic. The government has taken steps to realize the right to health. However, there are still many respects in which it needs to implement further measures to ensure respect for, protection and progressive fulfilment of the right to health of the population in relation to HIV/AIDS.

HIV/AIDS-related stigma and the discrimination resulting from it pose a key barrier to successfully implementing treatment, care and prevention programmes. It ultimately limits people's rights being fulfilled and protected. Unchecked discrimination against certain sectors of the population in Guyana increases their risk of HIV infection.

The indigenous Amerindian population of Guyana has limited access to essential medicines, or health care beyond basic provisions, such as painkillers. There is a lack of adequate and appropriate HIV/AIDS-related information and education for Amerindians, including information in indigenous languages. They also lack adequate representation in and influence over the policy-making processes relating to the epidemic.

Gender-based violence needs to be addressed and women need to be provided with adequate support and protection. HIV/AIDS treatment programmes and clinics need to actively reach out and include men in testing, in PMTCT and treatment programmes, and ensure that women who are not pregnant have equal access to prevention, treatment, care and support, including through the provision of sexual and reproductive health services to the whole population.

Men who have sex with men are criminalized, discriminated against, and face restricted opportunities to access appropriate HIV/AIDS prevention, treatment and care. A lack of targeted interventions and support organizations means their right to health and its underlying determinants is undermined.

The authorities are failing to protect the rights of people living with HIV/AIDS in the workplace. There is currently no mechanism or ombudsman through which people living with HIV/AIDS or affected by it can make a complaint in relation to HIV/AIDS discrimination

without compromising their right to privacy. Given the level of stigma associated with the disease, this denies people an effective remedy.

Access to prevention and treatment, including antiretroviral medicines, is dependent on where you live. The access of children to antiretroviral treatment is even more limited.

Inadequate structures in the health system or negligence of medical staff frequently deny patients their right to privacy and confidentiality. In an atmosphere characterized by stigma and fear, violations of the rights to privacy and confidentiality are contributing to the spread of HIV/AIDS by discouraging people from seeking an HIV test or preventive tools and/or adhering to treatment.

The way in which the response to HIV/AIDS is structured in Guyana denies civil society, including people living with HIV/AIDS, their right to participation. This failure limits the effectiveness of prevention, treatment, care and support by failing to adequately integrate and address the specific needs of affected groups.

Access to methods of preventing HIV infection -- including comprehensive education, information, and barrier prevention methods, such as condoms, and comprehensive sexual and reproductive health services -- varies considerably throughout the country. In many instances prevention services are provided through NGO's that have to fulfil conditions laid down by external funders fall short of these requirements.

To successfully address HIV/AIDS in Guyana, it is pivotal that donor governments do not link funding to conditions which might require the government of Guyana to break promises set out in the human rights standards it has committed itself to. Equally, in trying to maximize the impact of the funding that is currently available, the government of Guyana needs to ensure human rights are not compromised and form an integral part of all HIV/AIDS-related policy and programme activities.

The international community, and second governments, including in particular the USA, in seeking to respond to HIV/AIDS in Guyana, must equally ensure that its efforts respect, protect and fulfil human rights, particularly the right to health.

Recommendations on Guyana

To the government of Guyana:

Medicines

- With immediate effect, take measures to ensure access to essential medicines for HIV/AIDS, including antiretroviral treatment and treatment for opportunistic infections for the whole population, particularly people living in the hinterland, the indigenous Amerindian population, women and children.

Health Care

- Take steps to ensure progressively that health care is available, accessible, acceptable and of sufficient quality for the whole population by strengthening health services.

  Availability
  - Ensure an integrated health service is developed throughout the country. The service should encompass comprehensive sexual and reproductive health services and adequate supplies of essential medicines.
  - Progressively ensure the provision of tools for the prevention of HIV/AIDS for the whole population.
  - Immediately ensure that all testing is based on fully informed consent, includes pre- and post-test counselling, is confidential, and is implemented according to the standards set out in the UN Guidelines on HIV/AIDS and Human Rights. Progressively ensure that HIV testing is available to the entire population and is linked to adequate provisions for treatment, care and support.

  Accessibility
  - Progressively work towards ensuring that everyone has access to the health care they require, regardless of where they live, without having to travel for prolonged periods of time.

  Acceptability
  - Immediately adopt legislation safeguarding the right to privacy and ensure that confidentiality of HIV status is respected in health care settings and by medical and other staff in health facilities. Adopt and implement clear guidelines and appropriate sanctions for violators of the right to privacy. Work progressively to ensure that privacy is respected in the provision of health care and all health centres.

Gender

- Immediately exercise due diligence to prevent, investigate and punish all forms of gender-based violence and offer adequate support and protection for women who are at risk or have experienced such violence, including through the provision of free and accessible post-exposure prophylaxis and counselling, and a review of sexual

offences laws and their implementation to ensure they meet international human rights standards and offer adequate protection to women and girls.

- With immediate effect adopt measures that ensure all girls and women, especially women in marriage and young women, have full access to HIV/AIDS prevention, including comprehensive information and barrier prevention methods, such as condoms, and support the development of preventive methods which allow greater control by women, such as a microbicide.

Non-discrimination

- Adopt measures, including relevant legislation, to prohibit and sanction discrimination against people living with HIV/AIDS, including in the workplace.

- Ensure that where the rights of people living with HIV/AIDS have been violated there are accessible mechanisms to remedy their grievances, and that people living with HIV/AIDS are not discriminated against in their access to justice.

- De-criminalize homosexuality and include protection against discrimination on the basis of sexual orientation in the Constitution, and ensure that the rights, including the right to health and non-discrimination, of all men who have sex with men, and LGBT people are fully realized, including through adequate HIV/AIDS support and prevention programmes.

Information

- Take steps to ensure that the whole population, including young women and men, the population in the hinterland and the indigenous Amerindian population, has access to comprehensive, accessible and appropriate HIV/AIDS related information and education.

Participation

- Ensure the meaningful participation of people living with HIV/AIDS and civil society, in the decision-making and monitoring processes about all HIV/AIDS-related funding, policy and programming, including the participation of people living with HIV/AIDS, civil society and members of indigenous communities in the Presidential Commission on HIV/AIDS and the Health Sector Development Unit.

Recommendations to US government, other governments and donors

- Ensure that efforts to respond to HIV/AIDS respect, protect and fulfil human rights, particularly the right to health, and the rights of women, and the provisions outlined in the UN Charter and WHO Constitution.

- Ensure that all funding provided to support the response to HIV/AIDS in other countries does not contravene the recipient governments' obligations committed to in international human rights standards.
- Affirm commitment to the United Nations International Guidelines on HIV/AIDS and Human Rights and ensure design and implementation of responses to HIV/AIDS is in accordance with the guidance summarized in these.