

HIV and AIDS in Haiti



Nick Caistor, Jean Hugues Henrys and Anne Street

About this book

Haiti has the highest incidence of HIV and AIDS in the world outside sub-Saharan Africa, yet years of political chaos have left the country ill-equipped to tackle the epidemic.

This report examines the political, social and economic situation which has allowed HIV and AIDS to flourish, and explores the responses of the Haitian government, NGOs and the international community. In findings that will resonate with the experience of HIV and AIDS in other developing countries across the world, the report shows that the deep, grinding poverty faced by millions of people in Haiti puts those living in poor communities at greatest risk, and argues that HIV and AIDS cannot be tackled without also addressing the endemic poverty and injustice in the country.

About the authors

Nick Caistor is a former BBC World Service journalist who has been visiting and reporting on Haiti since 1990. In 2003 he carried out interviews in Port-au-Prince and the countryside with people concerned with the HIV and AIDS problem.

Jean Hugues Henrys is a Haitian medical doctor, specialising in public health. He is the vice dean and chief of the public health department of the Faculty of Medicine of the Catholic University of Haiti, Université Notre Dame d'Haiti. He also works as an independent consultant, and has undertaken studies of HIV and AIDS in Haiti.

Anne Street was at the time of writing advocacy coordinator for Progressio in Latin America and the Caribbean. She is the author of *Haiti 2004: A nation in crisis* and has had a long-standing interest in and concern for Haiti and its people.

Interviews with Haitians living with HIV and AIDS were carried out by Gianni Dal Mas, an advisor in communications and human rights working as a Progressio development worker in the Dominican Republic.

Additional interview material was provided by Calixte Clérismé, Director of the Centre for Development Research, Port-au-Prince, Haiti.

Contents

	Luisan's story	4
1	Introduction.....	6
2	Haiti in history	7
3	Haiti's population.....	9
4	The economic and social situation	10
5	The history of HIV and AIDS in Haiti	11
6	Awareness and knowledge of HIV and AIDS.....	14
7	Responses to HIV and AIDS	16
8	Treatment of HIV and AIDS patients	21
9	Stigma and discrimination	22
10	People Living with HIV and AIDS (PLHA) associations	25
11	Religious groups	26
12	Traditional medicine and voodoo beliefs	28
13	HIV and AIDS and the Dominican Republic	30
14	Conclusions	31
	References.....	32

Luisan's story

I am 47; I live in Port-au-Prince, the capital of Haiti. I have four children, three boys and a girl. I am a street seller of food.

My husband died of AIDS in October 2000. In the last year when he was ill, he never told me what his illness was. I was ill too and it was a difficult situation because I didn't know what illness I had. I used to think that HIV was black magic that someone put on a person. So when I began to be ill, I thought it was voodoo witchcraft that someone had put on me.

I know now that I am HIV positive but luckily I haven't got AIDS yet. Even so, I lost my two older sons through the disease: they went to live with other families when they knew that I was HIV positive, and they have no dealings with me now, nor do they recognise me as their mother. If anyone asks them, they don't say I am their mother and neither do they take care of me. The people with whom they went to live taught them to avoid people with the disease.

I had my first HIV test after the death of my husband. I was getting very thin and weak, and people were murmuring that my husband had died of AIDS. It was several months before I had the courage to go for the test. I was very afraid that the result of the analysis would confirm that I had the same disease as my husband and that I was also going to die. I was afraid that people would point me out as someone with AIDS. I decided to return to the town where I grew up, near Cap-Haïtien, as I still had friends there who could help me if I needed anything. I was sure that I would find in the hospital there someone who could advise me and tell me the truth. In Port-au-Prince I didn't know anyone I could trust.

When they told me, I became very sad. I left the hospital and went to the riverbank. I sat down to think of all the things going round and round in my head. What would become of my children? If I was going to die, who would look after my little girl and my sons? My family had no money to send them to school and I couldn't tell anyone that I had this disease ...

No, I didn't tell anyone because I knew that people would begin to shun me and humiliate me, just as they had begun the rumours about the death of my husband. This is a disease that everyone is afraid of. Everybody was whispering that a disease had come to the country that first makes you thin and then kills you. And I had those same symptoms. People said that when a person had AIDS nobody wanted to sit beside them, they don't want to eat or sleep near them. Everybody is afraid of it. When they gave me the results of the test, I was afraid that people would do the same with me.

So I did not want to believe the results ... They told me a lot of things about the virus and how the disease was transmitted, but my head was full of beliefs and confusion. I returned to the voodoo priest's house and spent more money on that, with worse results.

Eventually I went back to speak to a nurse in the hospital in my home town, and I asked her if what the people were saying was true. She told me that I should be tested again to make sure that I had the virus and that there was medication that could help me to live an almost normal life. At that time I didn't want to believe her. On the one hand I was afraid of the discrimination, and on the other I thought that the voodoo priest could find a remedy for my problems.

When I finally had another test, here in Port-au-Prince in 2003, the first person I told was a woman who was in the clinic with me. She had just come out of the post-test consultation and I asked her what they had told her. I realised that we were in the same situation and that we were both afraid. But they had also told us that they would give us another type of test so that they could give us the medication that we needed, and the next week we went to another organisation which included us in a support group. Now we are good friends and we help each other.

Today, after knowing the illness better, I'm no longer afraid of telling people. That is the best way for people to avoid getting infected themselves. I know now that it is not a sin to have HIV, that we can all have HIV: the poor, the rich, Catholics or Protestants ...

The first person I told in my family was my smallest daughter. She knows that I need the medication and it is she who helps to remind me every day what time I have to take them. The ones who reacted worst were my two older sons. They hadn't got the information that I had been able to get during the consultation and they began to be afraid of me, until eventually they left the house. One of my sisters took my sons into her house and then, thanks to the help of another friend, they helped them to leave the country. Now they have a better life in another country ...

It makes me sad that most of the discrimination came from my own home. I often think of the effort I made to send my sons to school and college. Now they are far away and don't help me to get on in this situation. I am 47 and I need to eat well, drink well and not have upsets: I need their help, not their discrimination and stigmatisation.

I go to my sister's house, but she doesn't like it much. I sit down with her and with the others and show them that a person with the virus is like everyone else. One has to recognise the illness and know how it is transmitted in order to know how to avoid the disease. Do you know that one of the biggest problems is that there are a lot of people who still do not believe that the illness really exists? Now that I am well again thanks to the anti-retrovirals, people see me well, they see my healthy skin and that I am no longer thin. They think that it was really about a spell that had been put on me ... they go on believing that AIDS is only witchcraft done by someone who wants to harm you. Luckily for me I didn't have any more money to pay for the services of a voodoo healer and I was able to get the anti-retrovirals free. That saved my life.

The relationship with my family and especially with my sister is already not the same. She no longer treats me like a true sister. The discrimination and the fear that she feels prevent things from being the same as they were. They do not visit me at home, and the few times they did it was obvious that they were not at ease with me.

I don't see my sons who are abroad ... they call from time to time, the last time was a month ago. They call to speak to their little sister and they ask her about me. They ask her if I am ill, and she says no. They ask if I am in bed, and she tells them no. They don't believe either that I have HIV, they don't believe that the anti-retrovirals are saving my life.

There is a lot of discrimination because there are many sick people in Haiti, and many have already died from AIDS. I do not think that I will die of it, and I hope to go ahead and help others not to get infected.

AIDS does not kill, it is discrimination that kills.

Interview by Gianni Dal Mas, 2006. Luisan is not her real name.

1: Introduction

The HIV and AIDS pandemic represents a major global challenge. It is not only in the worst affected countries in sub-Saharan Africa that the situation is critical. There are other parts of the world where the impact of HIV and AIDS, although less publicised, is devastating communities and presents a serious threat to national governments. Haiti has the highest incidence of HIV and AIDS in the world outside sub-Saharan Africa, yet few people in the UK, if asked which countries outside Africa are worst affected, would mention it. India, China or Thailand might spring to mind, but not Haiti.

This publication attempts to redress that imbalance. Progressio (formerly CIIR) has had a long connection with Haiti. From speaking out against human rights violations under the Duvalier dictatorship, to backing the efforts of charismatic priest-turned-president Jean-Bertrand Aristide to challenge inequality and injustice, Progressio has campaigned to support our partner organisations' struggles for equitable development in Haiti. In 1994 Progressio (then CIIR) opened a skill-share programme in Haiti, prioritising sustainable agriculture, gender equity and communications. Since then Progressio has supported non-governmental organisations (NGOs) and community organisations through the placement of skilled development workers and through international advocacy aimed at influencing policy-makers in the UK and Europe.

By highlighting the effects of HIV and AIDS in Haiti for a European audience, Progressio seeks to tell another story behind the headlines of poverty, insecurity, violence and military interventions. In a country as poor as Haiti, with a weak government and lacking rural infrastructure, it is often hard to gather reliable data on rates of HIV infection. It is clear nevertheless that HIV is a silent killer in Haiti, prevalent in poor communities where people often lack the education and resources to protect themselves adequately.

Progressio hopes that this report will serve to support the work of the many dedicated and hard-working health workers, NGOs and Haitian community organisations working to prevent and treat HIV and AIDS and working with the increasing number of individuals and families who are affected.

Progressio hopes that this report may also be useful for people and organisations working on HIV and AIDS in other countries throughout the world. The issue of HIV and AIDS has long been a key strategic area of work for Progressio. Many Progressio development workers are working with partner organisations in countries across the world, including in the border areas of the Dominican Republic and Haiti, to help them respond effectively to HIV and AIDS. We believe the findings of this report will resonate with the experience of tackling HIV and AIDS in other developing countries. By demonstrating the reality of living with HIV and AIDS in a poor country, this report underlines that those living in poor communities are most at risk from the epidemic, and least able to cope with its consequences. It demonstrates Progressio's belief that a comprehensive approach to HIV and AIDS prevention and care means that endemic poverty and injustice must also be addressed.

2: Haiti in history

On 1 January 2004, Haiti celebrated 200 years as an independent republic. Situated on the western third of the Caribbean island the Spaniards called Hispaniola, it was discovered for Europeans by Christopher Columbus, who landed on the island in 1492 during his first voyage. At first colonised by Spaniards, after the Treaty of Ryswick in 1697 Haiti became a French colony. It remained under French control until 1804, despite various attempts by the British and Dutch to take it over.

The indigenous population of Arawaks and Caribs was quickly wiped out after the Europeans arrived, and the Spaniards started to bring in black slaves from west Africa to work on sugar, coffee and other plantations. The proportion of white and mixed race inhabitants to the black population was always small: at the end of the 18th century it was estimated there were 31,000 whites, 28,000 'free coloureds', and half a million black slaves (Dubois 2004, p30).

Following the French Revolution in 1789, one of the French commissioners sent to Haiti proposed abolishing slavery in the colony. Armies of freed slaves rallied under the charismatic Haitian slave leader Toussaint Louverture but had to face incursions from the British and Spanish before taking on the French troops sent by Napoleon to restore order in 1802. At the end of 1803, the French army suffered its final defeat at the battle of Vertières, in the north of Haiti. The triumphant Haitians declared an independent republic on 1 January 1804, making Haiti the second independent country in the Americas (after the United States), and the first black republic in the world.

The new Haitian republic immediately faced hostility from the colonial powers. It was not until 1825 that France formally recognised the independence of its former colony, while continuing to demand huge reparations for loss of land and property. Poverty and political instability soon became endemic to the new nation, with landowners, freed slaves and the small mixed race population jostling for power. Despite the shared struggle for independence, relations with the United States were also difficult. The United States only recognised Haiti's independence in 1862, and in 1915 US troops invaded Haiti, claiming the government had not paid its debts to the United States. The US occupation lasted almost 20 years, and exacerbated the suspicion and sense of grievance many Haitians felt towards the outside world.

For several years after the US withdrawal in 1934, Haiti enjoyed modest progress and development, based on traditional exports of sugar, coffee and rum. The capital, Port-au-Prince, became a modern port, and grand buildings were constructed. This period of relative stability came to an end in 1957 when François (Papa Doc) Duvalier was voted into power. During his presidency, the rule of law was constantly undermined, until his rule became based on terror. Gangs of thugs, known as *tontons-macoute*, were used to keep order in the cities and countryside. Despite his medical background, Papa Doc was a strong supporter of voodoo and other traditional practices, and reinforced suspicion of modern medicine as 'foreign' and untrustworthy.

When François Duvalier died in 1971, his son Jean-Claude (Baby Doc) continued his misrule, further destroying the country's hopes for economic prosperity and good governance. By the time Baby Doc was finally thrown out in 1986, he and his father had made Haiti the poorest country in the western hemisphere. Many of the most talented Haitians, including hundreds of qualified doctors and nurses, had migrated to the United States, Canada and other countries. Democratic rule had been replaced by the use of force, and widespread corruption had destroyed the population's belief in the efficacy of government at any level.

A new democratic national constitution was passed in 1987. This did not mean that democracy was immediately ushered in, as various factions in the army fought to fill the power vacuum. In December 1990 a charismatic young Catholic priest, Jean-Bertrand Aristide, was elected president at the head of a

massive grassroots movement known as Lavalas. These elections were the first fair and free vote that Haitians had enjoyed since the end of Duvalierism, and hopes were high throughout Haiti that a new era of peace and honest government would follow.

This hope lasted only nine months, until an army coup in September 1991 swept Aristide from power. The armed forces repressed Lavalas and other popular movements, dedicated themselves to getting rich from corruption and the illegal drugs trade, and shut down parliament. The United Nations established a trade embargo against the military regime, but it was not until the number of desperate Haitian boat people trying to cross the Caribbean to Florida swelled into thousands that the United States reacted firmly.

US troops returned to Haiti in October 1994, and Aristide was restored to the presidency. One of his first acts was to disband the army, but he had little chance to implement other reforms because, as agreed with the White House, he left power in 1996 – the end of his original elected term of office. Meanwhile the United Nations had established a strong presence in Haiti, aimed at bolstering the police, justice and penal systems, and coordinating efforts to fight the growing epidemic of HIV and AIDS.

When in 1996 Aristide handed over the presidency to a close follower, René Préval, it seemed once again that Haiti had a chance to recover. Although still dangerously short of funds, the new government offered coherent proposals and had the backing of the United Nations and the rest of the international community. A fresh sense of optimism arose.

Once again, the optimism proved short-lived. Disputed elections in the year 2000, and Aristide's refusal to compromise on his return to power for a third time, led to the United Nations pulling out and to the paralysis of institutional rule. The country became increasingly divided between those who supported Aristide and those who accused him of becoming like his predecessors: more concerned with keeping himself in power than with promoting the well-being of all Haitians.

After several months of growing violence in the north and centre of Haiti, President Aristide was again forced to flee the country on 29 February 2004. The United Nations sent more than 7,000 troops to try to restore peace and calm, and a transitional government was appointed to organise elections. The elections, which were finally held in April 2006, saw René Préval return as president in May 2006.

There has been fierce debate in Haiti and internationally as to whether Aristide was overthrown by a genuine popular upsurge rejecting his rule, or whether the violence was instigated by former members of the army and supporters of the 1991-1994 military regime. Whatever the truth, the consequences for ordinary Haitians were the collapse of the national government, the prevalence of violence over reasoned argument, and severe disruption of economic activity at all levels, leading to further impoverishment.

This troubled history has many consequences for the fight against HIV and AIDS. Because of their harsh treatment by the colonial powers and by the United States, many Haitians mistrust foreign intervention in any area of their lives. They cling to a nationalism which at its most positive has helped create a strong sense of cultural identity, but which can be negative when a collaborative effort, such as that required to combat HIV and AIDS, is needed.

The lack of effective democratic government for many years also makes many Haitians suspicious of any initiative taken by the state. After witnessing so much corruption and misinformation, many want to have as little as possible to do with anyone in authority, which makes official campaigns against the disease all the more difficult to implement. At the same time, the lack of a functioning state apparatus makes it harder for central or local government to collect taxes and to apply the revenue collected in any sustained, coherent way. This is a severe obstacle to the provision of health care, and means that any sustained fight against HIV and AIDS in Haiti faces significant problems.

3: Haiti's population

According to the most recent censuses, Haiti's overall population is 8.3 million (UNDP 2005, p234). The 1982 national census put the figure at 5,053,792 (University of Utrecht Population Statistics www.library.uu.nl/wesp/populstat/Americas/haitig.htm) which means that the population has increased by more than 50 per cent in 20 years. Haiti's population remains one of the most rural in the western hemisphere, with between 60 and 65 per cent of people living in the countryside, and only about 35 per cent in cities and towns (UN Department of Economic and Social Affairs Population Division, <http://esa.un.org/unpp/>). There is, however, a constant and largely uncontrolled internal migration towards the towns and cities: the capital, Port-au-Prince, for example, has grown from a city of 750,000 to more than two million inhabitants in the past 30 years. Most of the new arrivals end up in the slum areas, which account for close to half of the total land area of the city.

There is also a huge emigration from Haiti. More than half a million Haitians now live in the United States, while up to half a million Haitian migrant workers and their descendants are estimated to live in the Dominican Republic. Significant numbers of Haitians have also emigrated to French-speaking Canada and to France.

Haiti is a predominantly young country: 38.6 per cent of the population are under the age of 15 (UNDP 2005, p234). But few Haitians live to old age. Average life expectancy is only 50 years, and has decreased by seven years over the past quarter of a century owing to the impact of AIDS (UNAIDS/WHO 2004, p1). Among women aged between 15 and 49, AIDS is the leading cause of death, and accounts for 20.5 per cent of deaths with a well-defined cause. An analysis of the causes of death in the general population (based on a study of hospital death certificates begun in 1997) shows that AIDS was the primary cause of death, representing 5.2 per cent of the total (UNAIDS/WHO 2002).

The rapid growth in population, especially among those of child-bearing age, makes the HIV and AIDS epidemic hard to control. So too does the fact that so many Haitians are either internal migrants or seek to live and work abroad, and often come and go between Haiti and another country. This makes it hard to establish reliable epidemiological data to help prevent HIV infection, and makes treatment and supervision even more difficult.

The poverty in which most Haitians live is also a major contributing factor to the spread of HIV and AIDS. The often crowded living conditions in Haiti's ever-expanding slums lead to stress; the lack of hygiene and inaccessibility of clean water make it more difficult to combat the 'opportunistic' diseases associated with AIDS, such as pneumonia; and rates of malnutrition and under-nutrition among the very young are high. Many of Haiti's poorest people have little access to health care, and the government's educational campaigns on HIV and AIDS and other health issues fail to reach them. Few of those living with HIV and AIDS can afford to pay for drugs. Because people confront such high levels of insecurity in their daily lives, the challenges of embarking on a lengthy course of treatment are far greater.

4: The economic and social situation

For several decades now, Haiti has been known as the poorest country in the western hemisphere. In 2003, annual per capita income was estimated at an average of only US\$346 (UNDP 2005, p268): only one dollar a day. The United Nations Development Programme (UNDP) estimates that 56 per cent of Haitians live in conditions of extreme poverty, and 77.6 per cent in poverty (extreme poverty is defined as an income of US\$1 a day, and poverty as US\$2 a day).

Haiti's gross domestic product has stayed more or less the same as it was in 1985, but the population has grown by half in that time, suggesting a huge increase in poverty. Many people in the countryside live almost entirely outside the money economy. Estimates of the literacy rate suggest that only 53.8 per cent of Haitian men, and slightly fewer (50 per cent) of women, can read and write (UNDP 2005, p302).

The health statistics for Haiti make even more dramatic reading (PAHO/WHO 2004). The average mortality rate in 2004 was estimated at 14.3 per thousand. The infant mortality rate was 92 per thousand births, two and a half times that of the neighbouring Dominican Republic, while 136 children out of a thousand were expected to die before reaching the age of five. The maternal mortality rate was the highest in the western hemisphere, at 530 per 100,000 live births.

Many of the main health problems in Haiti are directly related to poverty and inadequate housing. They include diseases related to malnutrition, infection, parasites and tuberculosis, as well as HIV and other sexually transmitted infections.

Although medical care is free in public hospitals and clinics, public health provision is limited and in practice Haitians have little access to proper medical attention. Very few people can afford health insurance. Because the state's resources have proved increasingly inadequate, more and more health care is now provided by religious groups, charities and international partnerships. In 2004, the United Nations calculated that only half the health care in Haiti was provided by the state (UNAIDS/WHO 2004).

5: The history of HIV and AIDS in Haiti

Internationally, the first cases of AIDS and the opportunistic diseases related to it were diagnosed in 1981 by the Centers for Disease Control (CDC) in Atlanta, Georgia (United States). The human immuno-deficiency virus itself was identified in 1983, and by 1987 AZT, the first drug to combat HIV infection, was being produced. By 1996 the more effective anti-retroviral therapy (ART), based on a combination of three drugs, was available in many developed countries. In the developed world, HIV is now increasingly viewed as a chronic rather than a fatal infection.

This is far from being the case in Haiti. The first reported case in the country dates from 1978, and was recorded by the Dermatology Service at the State University Hospital. The same hospital also noticed an upsurge in Kaposi's sarcoma cases, and Dr Bernard Liautaud, a specialist trained in France who had returned to Haiti at the end of the 1970s, helped set up the Groupe Haitien d'Etude du Sarcome de Kaposi et des Infections Opportunistes (GHESKIO – Haitian group for the study of Kaposi's sarcoma and opportunistic infections), which was responsible for the first attempts to study and monitor the epidemic.

In the United States, cases of HIV/AIDS were found among Haitians in 1981, and as a consequence in 1982 the CDC in Atlanta included Haitians as one of the 'four Hs' – the other three were homosexuals, heroin addicts and haemophiliacs – seen as most susceptible to contracting HIV and AIDS.

This inclusion of a nationality as among those most at risk of the newly-discovered illness caused uproar in Haiti. The doctors involved in GHESKIO took the lead in denouncing the racism of the attribution, and were instrumental in having Haitians withdrawn from the CDC list in 1986.

It has since become widely accepted that the first incidences of HIV/AIDS in Haiti were probably the result of homosexual tourist sex with visitors from the United States. In the 1970s, despite the oppressive Duvalier regime, tens of thousands of foreign tourists visited Haiti: in 1980 for example, the number of tourists reached almost 200,000, most of them coming from the United States (Farmer 1992, p146). The rumours about AIDS possibly originating in Haiti were seen by many local figures as a continuation of the historical prejudice against Haitians (see for example Farmer, 1992).

As in other countries, in Haiti HIV and AIDS at first mainly affected the homosexual population. In the early 1990s it was estimated that six Haitian men were infected to every woman, but this profile has changed rapidly. The disease now affects both sexes in more or less the same proportions. The incidence of vertical transmission, that is between an infected mother and her child, has been put at 4,000 cases in 2003 alone (UNAIDS/WHO 2004, p4). In March 2003 a pilot programme to help prevent mother-to-child transmission was set up by CHOSCAL, a partnership between the Haitian Ministry of Health, GHESKIO, and UNICEF.

The UNAIDS (Joint United Nations Programmes on HIV/AIDS) report for 2004 (UNAIDS/WHO 2004, p1) confirms that Haiti is worse affected by HIV and AIDS than any other country outside sub-Saharan Africa. More than half of all those infected with HIV in the Caribbean live in Haiti, and up to 85 per cent of all cases in the region are to be found either in Haiti or the neighbouring Dominican Republic (where the authorities put the blame for high infection rates on the large numbers of Haitian migrant workers). (Interview with Raúl Boyle, 2003.)

Raúl Boyle: UNAIDS country coordinator in Haiti since 2003

The basic problem for the spread of HIV and AIDS is the economic situation. AIDS is not only a health problem, it's much more a development problem. The linkage between Haiti and that of some African countries is because of the development situation. By that I mean the lack of education, poor housing, promiscuity, lack of hygiene, and so on. But even in this economic and political situation, there is a window of hope. According to the latest epidemiological surveys, the rate of the epidemic has stabilised – at a high level, because we are talking about between five and six per cent, which means that one in 20 people are infected, but this is more or less the same as it was some years ago. The explosion that was feared as one of the scenarios has not happened. Now the big effort of everyone working on HIV and AIDS in the country is to try to lower the level of the epidemic. And this is possible, because in Haiti there are many institutions which are doing excellent work both in prevention and in care and treatment.

Interview by Nick Caistor, 2003.

Epidemiological statistics are very hard to come by. For some years in the 1990s AIDS case reports were not even collected. The most reliable and up-to-date figures are those provided by UNAIDS. Its estimates for 2005, from its *2006 Report on the Global AIDS Epidemic* (Annex 1: Country Profiles: Haiti), are reproduced in the table below.

HIV and AIDS statistics for Haiti, 2005

Number of people living with HIV	190,000 (120,000 – 270,000)
Adults aged 15-49 HIV prevalence rate	3.8% (2.2% – 5.4%)
Adults aged 15 and over living with HIV	180,000 (100,000 – 250,000)
Women aged 15 and over living with HIV	96,000 (50,000 – 150,000)
Children aged 0-14 living with HIV	17,000 (5,800 – 36,000)
Deaths due to AIDS	16,000 (9,500 – 24,000)

Source: http://data.unaids.org/pub/GlobalReport/2006/2006_GR_ANN1G-L_en.pdf

In a 2004 report, UNAIDS stated that according to 'sentinel studies' carried out on pregnant women in 12 sites throughout Haiti, there could be a national prevalence of 4.5 per cent, whereas a 1996 study from nine sentinel sites suggested a national average of 5.9 per cent. However, the authors of the report advised caution in the interpretation of these results, pointing out that 'it is impossible to ensure that the difference in prevalence reflects preventive behaviour among the population. The analyses of the causes of death, which started with the collection of hospital death certificates in 1997, show that AIDS is the leading cause of death at the national level' (UNAIDS/WHO 2004, p4).

An earlier study, also by the United Nations and published in 2003, estimated the number of adults with advanced HIV infection needing anti-retroviral therapy to be around 40,000, whereas only 1,370 were actually receiving the treatment (WHO 2004, p1).

One of the groups most affected by HIV and AIDS is sex workers of both sexes. Little data has been collected about the impact on this group, but data collected between 1986 and 1992 showed 'HIV prevalence among sex workers tested in the major urban areas ranged from 42% in 1989, to 65% in 1992' (WHO 2004, p2).

Madame Jacques Guerda: sex worker

Everywhere you go, you hear of one big concern: AIDS. You have to be very careful. It does not matter whether you are rich or poor, you are the one who must be careful, you are the one who must erect a barrier against it. Some men, as soon as they enter the room with you, ask how much they have to pay. If you answer, say, 30 Haitian dollars, they say 'I'll add another 10 in order not to use a condom.' And if the woman answers no, immediately some of them who are either high or drunk will say 'I'll kill you if you don't accept,' or start hitting you.

A friend of mine was submitted to that kind of pressure. Once, we were in a cabaret in the Carrefour neighbourhood south of the capital when a man living abroad approached my friend and asked how much he had to pay to spend some time with her. The girl said: 'If you want to spend the night, it will be US\$150.' He said 'OK, I'll spend the night with you, and pay you US\$250 for not using a condom.' And the girl agreed. She was very lucky not to catch HIV, but she did get an infection. I told her where to go for a medical test, and she went and explained the problem. They found the right medicine for her. So the individual must always exercise self-control, and avoid the money temptation.

Interview by Calixte Clérismé, 2003.

6: Awareness and knowledge of HIV and AIDS

Modlyn Alphonse: from Wanament on the Haiti-Dominican Republic border

Before I had the [HIV] test, I didn't know anything. It was only when I knew that I was positive that I began to know a whole lot of things that one shouldn't do in order not to get infected with the virus. I had never been told about the use of the condom, about transmission through the blood and all the things I know now. I didn't know how to protect myself against infection, and I hadn't looked for the information.

I never thought that I would have a problem like this ... It never entered my head that this illness could come to me.

Interview by Gianni Dal Mas, 2006. Modlyn Alphonse is not her real name.

Despite government and NGO information campaigns, a continuing lack of awareness of what exactly is the human immuno-deficiency virus contributes to the spread of the disease. One of the main reasons for this lack of knowledge is the fact that only between 50 and 60 per cent of Haitian children complete primary school education, and only one in five go on to secondary school (PAHO/WHO 2004).

Liony Accelus: social worker for Promoteurs Objectif Zerosida (POZ)

I had taken part in some training courses organised by the hospital in Leyógan in 1999, where they explained the meaning of HIV and AIDS, the danger of having sex without protection and also how to use these protections, the condoms. Even with all this information, in those days we classified AIDS as an illness which only affected some sectors of society: people with money, who travel a lot to other places ... We thought the poor like us could not become infected with this virus. At that time the most famous sentence for information on AIDS was 'we can all have it', but I understood its meaning too late. At that time I thought that people like me couldn't be affected by an illness like that.

I had been ill for some time but I went on working as a lorry driver. One day I had a serious accident. A friend suggested that it could have been an evil eye that had caused it, and when I saw that I was not recovering from the illness, I thought that the illness itself could have been caused by the same evil eye, done by someone who wanted to kill me. My friends began to tell me to hurry up and get treatment because the evil eye would have killed me very quickly. I used all the money I had looking for a solution with a witch doctor.

The first person to advise me to have the HIV test was my sister: when she saw that I had got so thin, she told me that someone like me, who liked women so much, should have the HIV test. The deal was that if the test showed that I was positive, she would help me financially; but if I continued to give money to the witch doctors, she would leave me on my own. This was a sort of blackmail, and I only accepted when I had no more money to pay for the voodoo remedies. Then I went to my sister's, here in Port-au-Prince. We called the 'blue number' [free line to ask for information on HIV and AIDS, dialling 100], and I told them of all the symptoms in my body. The person on the other end of the telephone told me: 'My dear, it could be that you have HIV

or it could be that you haven't got it. The only way to find out is to have the test.' And the result was positive.

Interview by Gianni Dal Mas, 2006.

A study conducted in 2003 (PAHO/WHO 2004) showed that the percentage of young people aged 15-24 who could correctly identify two ways of preventing the sexual transmission of HIV and who rejected three misconceptions about HIV transmission was extremely low: among males it was 24 per cent; among females a mere 14 per cent. In the same age group, the proportion of males who said they had sexual relations with a non-regular partner was 93 per cent; while 59 per cent of females fell into the same category. The use of a condom for sexual activity was put at 30 per cent for males, whereas only 19 per cent of females said they used protection.

Nathan: US Peace Corps volunteer working in a village in northern Haiti

I work in a remote village, where there are about 6,000 or 7,000 people altogether. There are no telephones, no radio, there is no drinking water. It's hard to say whether the AIDS epidemic is noticeable, because people die every day, or go missing. People begin to be sexually active very young, sometimes as early as eight or 10 years old. But people are starting to become aware of AIDS, and I'd like to think that young people are changing their behaviour. But only a small percentage of them use condoms; they can go to one of the two dispensaries in the village and get them for free, but many young people are embarrassed about this, so I keep a stash so they can come to me for them. But there's still a great ignorance of what they are and how they work.

Interview by Nick Caistor, 2003.

7: Responses to HIV and AIDS

The state

In contrast to its slowness to react to other social problems, the Haitian state responded quickly and with some success to the spread of HIV and AIDS. This may in part have been a response to the stigmatisation of all Haitians, when the CDC in the United States labelled them as one of the 'four Hs' who were particularly susceptible to the disease. The fact is that all the governments in power since HIV and AIDS were first identified have seen it as a public health priority.

At the end of the 1980s, the National Programme for the Fight Against Sexually Transmitted Diseases and HIV Infection was launched. The health ministry set up a high-ranking team to supervise this programme, which is made up of eight members of the government and eight members representing NGOs, the private sector, professional associations, and multilateral and bilateral organisations.

Their task is to ensure that HIV and AIDS remain a priority in public health; to keep abreast of research worldwide into the disease and methods of prevention and treatment, and inform the Haitian population of these advances; and to track the Haitian response to the HIV and AIDS epidemic, especially with regard to prevention, health care, research, and use of resources. The health ministry team is also charged with studying the ethical implications of the disease and with submitting all its recommendations to the minister.

Until 2002, the government programme to combat the spread of HIV was based on two main areas of activity. The first area consisted of preventive and educational efforts designed to reduce vulnerability and promote sexual behaviour that would reduce risk. Attempts were also made to increase surveillance of HIV-positive mothers to avoid transmission of the virus to their children. There is some evidence, albeit inconclusive, that this campaign did reduce the incidence of mothers passing the disease on to their offspring.

There has also been a sustained campaign to increase the production and use of condoms. In the late 1980s, only a few thousand condoms were made or distributed in Haiti. By 2001 this had risen to 12 million (personal information of John Hugues Henrys, quoted in Street 2004, p15) and in 2005 one agency, the US-based President's Emergency Plan for HIV/AIDS Relief (PEPFAR), planned to distribute seven million free condoms. An educational campaign in the written press and on radio and television has accompanied these efforts, but reports from villages and slum areas suggest that the actual use of condoms is low.

A concerted effort was also made to ensure the security of blood bank supplies. Since 1986 the sale of blood products has been prohibited; all aspects of collecting, supervising and selling blood are now carried out by the Haitian Red Cross Blood Transfusion Centre. There are plans to set up 10 blood transfusion centres and 49 blood transfusion posts throughout the country.

In March 2002, with the help of UNAIDS and other multilateral agencies, the Ministry of Public Health and Population produced a 'National Strategic Plan for the Prevention and Control of Sexually Transmitted Diseases and HIV/AIDS' (Ministère de la santé publique et de la population, 2002). This incorporated the three strategic objectives UNAIDS has set to combat the disease worldwide:

- Reducing risk. According to the plan, this means education and information schemes designed to make young people and others aware of the risk involved in unprotected sex with multiple partners, and to increase a sense of personal responsibility.

In addition, 27 voluntary counselling and testing centres have been set

up throughout the country. These centres are meant to offer integrated services for free and anonymous testing for sexually transmitted diseases and HIV.

- Lowering vulnerability. The plan proposes a partnership with the Ministry of Education to provide better information for young people and their parents on sexual matters, with particular emphasis on trying to persuade young people to begin sexual activity later.
- Diminishing the impact of the infection. The national plan calls for greater efforts to care for all people living with HIV and AIDS (PLHA). There is a commitment to provide care in public hospitals for those in advanced stages of AIDS, but a plan is also being drawn up for community care of PLHA.

Legislation specifically protecting the rights of PLHA has yet to be passed in Haiti, although similar legal protection has existed in the neighbouring Dominican Republic since 1993.

This strategic plan was the basis for Haiti's proposal to the Global Fund for the Fight Against AIDS. This was accepted at the end of 2002, with the result that US\$67 million was made available for the five years 2002-2006. The strategic plan has now been extended until 2010, under the leadership of the Ministry of Health and Population, with technical support and leadership coming from the Central Coordination Unit of the Haitian government.

Other attempts to harness international cooperation in the fight against HIV and AIDS have been less successful. The moratorium placed on international aid in 2000 meant that many schemes, particularly at grassroots level, could no longer operate. The political and social unrest at the end of 2003, which worsened after President Aristide was ousted in February 2004, made it difficult for the health ministry to implement any of its plans. By mid-2005, much of the country was controlled by armed gangs, so that local government-run health centres were struggling to survive. In these circumstances, proper monitoring and treatment of HIV and AIDS has become almost impossible. The disruptions to political and social life since 2002 have been so harmful that some observers fear that in the years to come, Haiti could see an upsurge in the HIV and AIDS epidemic.

NGOs

Because of the obvious inadequacies of the public health system in Haiti over the 25 years since the discovery of HIV, several NGOs have consistently played a leading role in the fight against the epidemic. The two most prominent among these are GHESKIO and the Zanmi Lasante clinics.

GHESKIO was created on 2 May 1982 by 13 Haitian health professionals. It was one of the first groups formed internationally after the US Centers for Disease Control defined AIDS as a recognisable disease in 1981. Based in a clinic in the rundown port area of Port-au-Prince, GHESKIO undertakes research and treatment of HIV and AIDS. It is linked with Cornell University in the United States, and has consistently attempted to bring together private, public, Haitian and international sectors to fight the epidemic. It is thanks to GHESKIO's research that much of the information on the epidemiology and transmission of HIV in Haiti is known.

Until 2004, GHESKIO was one of only two centres in the whole of Haiti providing anti-retroviral therapy. It does not charge for its services, but relies on funds from international agencies and private donors. This reliance on foreign funds and its links with a prestigious university in the United States have occasionally led to accusations in the US and Haitian media that the clinic uses poor Haitians as 'guinea pigs' to trial new AIDS drugs, without proper precautions. This is vigorously denied by Dr William Pape, the Haitian director of the clinic, and his staff. Dr Pape returned to Haiti from Cornell University in 1980, and first worked successfully on problems of diarrhoea in children, before turning his attention to HIV and AIDS.

Dr Joseph William Pape: director of GHESKIO

There is a big legislative gap in Haiti. For example, there is a law which states that children cannot receive medical treatment without their parents' consent. This needs to be changed, because many street children come to GHESKIO who are HIV positive, and as medical doctors we need to treat them, but find there is this legal obstacle in the way. Also, there is no legislation relating to the rights and responsibilities of HIV positive people, or workplace-related legislation.

Despite everything, I feel that Haiti's fight against HIV and AIDS has been very successful. This is due to a variety of factors. There have been dedicated NGOs involved right from the start, and they have worked together. And of course, government help was also critical from the beginning, and there has been a strong partnership, led by the Ministry of Health. The role of First Lady Mildred Aristide was also critical. Haiti had the first National AIDS Commission in the world, which includes five ministries, NGOs, as well as USAID, the Centers for Disease Control, and major donors such as France and Canada.

Interview by Anne Street, 2004.

Because of its position in one of the poorest parts of Port-au-Prince, the GHESKIO clinic found itself caught up in the violence surrounding the departure of President Jean-Bertrand Aristide at the end of February 2004. Its main clinic was looted, and many of the drugs stolen, but it has since been able to continue its research and treatment programme. However, its location continues to provide a major challenge for those who need to attend regularly for treatment, because of the violence and risks associated with making the journey to that part of the city.

Zanmi Lasante is run by a committed US-born doctor and anthropologist, Paul Farmer. He first came to Haiti in 1983 and was so appalled at the health situation in rural areas that he stayed to set up a clinic in 1987. Together with Partners in Health, its sister organisation in the United States, the clinic provides primary health care for HIV and AIDS sufferers and other patients in the central highlands village of Cange. The clinic sees some 1,000 patients a day on a free or almost free basis, and is the only HIV and tuberculosis hospital in the central mountain area. Zanmi Lasante places great emphasis on training local people as health assistants who can administer and supervise the proper use of anti-retroviral drugs.

As with many other organisations in the health sector, Zanmi Lasante's work was seriously affected by the moratorium on international development and humanitarian aid to Haiti after the disputed elections in 2000. This further reduced the ability of Haiti's health ministry to deal with HIV and AIDS, tuberculosis and other serious diseases. NGOs such as Partners in Health tried to replace official help as much as they could: the Cange clinic reported that almost 200,000 patients visited their hospital and medical clinic in 2002, an almost threefold increase over the previous 12 months (information from Paul Farmer). The current instability and lack of government control over many rural areas in Haiti have made the work of Zanmi Lasante all the more precarious.

Dr Paul Farmer: founder of Zanmi Lasante

We have to strengthen the public health sector. It's very weak. How can you take care of people with AIDS without the tools? The biggest challenge facing Haiti is resources and how to get them to people living with HIV or people at risk of HIV who could be protected. The AIDS stigma, gender inequality, poverty are all important as risk factors. However in my view the biggest challenge is getting resources, both human resources and things like diagnostics and primary health care and also anti-retroviral treatment, to the people who need them most.

Interview by Calixte Clérismé, 2003.

Many other national and international organisations are committed to combating HIV and AIDs in Haiti. Two of the most prominent local NGOs working to help prevent the spread of AIDS are the Fondation pour la Santé Reproductive et l'Education Familiale (FOSREF – Foundation for Reproductive Health and Family Education) and the Volontariat pour le Développement d'Haiti (Voluntary Service for the Development of Haiti).

FOSREF works mainly in the poorest areas of Port-au-Prince. It has a clinic in the central market, and does outreach work particularly among Haitian youth. It offers advice about HIV and AIDS and other sexually transmitted diseases, and also organises recreational and cultural activities for young people.

The Volontariat runs several 'young people's centres' in Haiti's cities. In these centres it offers information about HIV and AIDS and sexual matters. But perhaps its most important achievement to date has been the survey it conducted in 2004 into the sexuality of young people in Haiti. The survey aimed to offer broadly-based data which can be used to help change behaviour and thus reduce the risk of those from Haiti's most vulnerable age group contracting HIV.

Other groups working with young people include Promoteurs Objectif Zerosida (POZ). POZ has a wide variety of activities including an HIV telephone helpline, centres for voluntary counselling and testing, and support services for HIV positive people. It is currently working with 16 PLHA groups in different parts of the country, providing space to discuss their personal stories, problems, rights issues and so on, as well as working with churches and church leaders. It has a programme on sexual violence, working with women who have been sexually abused. It is one of the few organisations in the sector that openly employs HIV positive people. It recently received a large grant from the International AIDS Alliance to support the network of PLHA associations to challenge stigma and discrimination through advocacy work.

Other relevant initiatives include information campaigns by several women's organisations to inform the population about gender inequalities in Haiti. They are also pressing for better education and training possibilities for women, and the strengthening of women's capacity to be independent financially and to have more say over the number of children they have.

Unfortunately these plans to help lower vulnerability have come up against Haiti's harsh political and social realities. In the violence and disorder that followed the ousting of President Aristide, there have been many reports of the use of rape and sexual attacks to spread terror. Even though in November 2004 the transitional government brought in stiffer penalties for rape, in many areas of the country the rule of law does not operate. Even when people are arrested, the justice and penal systems cannot cope: few of the accused ever face trial, so there are no real sanctions for the perpetrators of these crimes.

The United Nations and other international bodies

UNAIDS is well established in Haiti. It coordinates national efforts to combat the spread of the epidemic and has established a database which provides the most reliable statistical information in a country where trustworthy information is a rare commodity. UNAIDS has set up programmes in the slums of Port-au-Prince and Cap-Haitien, the two largest cities in Haiti. It is working to expand access to anti-retroviral therapy, strengthen local capacity and improve the quality of services, as well as trying to integrate the voluntary counselling and testing services with programmes on tuberculosis, sexually transmitted diseases and prevention of mother to child transmission. The UNAIDS programme is attempting to reach out to the rural areas with a strong preventative emphasis, in an effort to educate and inform. According to UNAIDS, the feared explosion in the HIV infection rate has not materialised, and the incidence has stabilised at around five per cent (interview with Raúl Boyle, November 2003).

Despite the high level of funding (US\$67 million over five years, 2002-2007) the UNAIDS programme has been criticised in some quarters for spending too much money on administration and overheads and too little on those most in need.

The year 2004 saw the first benefits from the HIV and AIDS initiative launched by US President George W Bush. Known as the President's Emergency Plan for AIDS Relief (PEPFAR), it committed some US\$20 million to the fight against AIDS in Haiti in 2004, and planned to double that amount in 2005. One of the main aims of this plan was to increase the number of patients who received regular and reliable anti-retroviral treatment, administered by GHESKIO and Zanmi Lasante. According to PEPFAR, some 2,800 persons were receiving this treatment by September 2004, and 3,900 by the end of March 2005 (www.pepfarhaiti.com/NewPepfar/Document/documents/presplan.pdf). The target is to provide secure anti-retroviral drugs to as many as 25,000 Haitians by the end of 2008.

However, there are some real problems in relation to anti-retroviral drugs with both the PEPFAR and UNAIDS programmes. With an ambitious target for increasing the number of HIV positive people receiving ART, the cost of the drug therapy is obviously important. One NGO using ART to treat women who have been raped or sexually abused spends US\$5,000 for a three-month supply from a US pharmaceutical company (personal communication, Rachel Stredwick, HIV Programme Funding Manager, Christian Aid). Generic drugs are available for use in ART and are much cheaper than brand name drugs. However, the interim government, heavily lobbied by the US pharmaceutical companies, has made no move to increase the supply of the cheaper generic drugs, which could end up saving many more lives (Stredwick 2005). PEPFAR currently funds 34 organisations, and according to HIV activists in Port-au-Prince, three-quarters of these are US pharmaceutical companies.

For its part, UNICEF has concentrated on efforts to reduce transmission of the disease from mother to child. This work is often carried out in partnership with non-profit making organisations from the private sector. UNICEF in Haiti has also investigated the use of underage children (the vast majority of them young girls) as domestic servants, and the frequent sexual abuse that they suffer (see also NCHR 2000.)

The US Agency for International Development (USAID) meanwhile has concentrated on trying to fight the chronic problem of poverty in Haiti. Together with Haitian organisations, USAID supports micro-credit schemes and other revenue-producing projects. Some of its projects, such as HS2004 and PL-480 (food aid), include specific plans to distribute food aid to people suffering from AIDS or tuberculosis (40 per cent of the latter are HIV-positive).

The Canadian International Development Agency also does important work in its 'Kore Fanm' projects. These are designed to help empower Haitian women. There are plans to set up a scheme which will cover the northern Artibonite region, working specifically on HIV and AIDS prevention.

8: Treatment of HIV and AIDS patients

Liony Accelus: social worker for Promoteurs Objectif Zerosida (POZ)

Before I knew that I had HIV, I went to a doctor who recommended me to have a series of analyses, but I didn't know which exactly. When I returned to the clinic and the doctor saw me arrive, he stood in the doorway and said: 'Sir, you can go and come back in three months.' At that time, shortly before doing the HIV test [at another clinic], I was very ill, and the doctor certainly thought that I was not going to live the next three months. Today I remember the faces of the people who were in the clinic when the doctor threw me out: they looked at me closely and I knew that it was because I was very thin and ugly. They understood very well what the doctor's words meant.

When I got the result of my HIV test I thought that the only solution was to move to another province, where no-one would know me, and that there I could await death calmly. Then everything would end. Or I had the choice of killing myself first ... I had these thoughts for two, three, four, six months, until finally I found the medication in a clinic in the Plato Central zone. I came to know another youth who was also looking for medication, and he gave me hope, because he confirmed that with the medication, persons infected with HIV don't die. And if they don't die, then neither should I.

Interview by Gianni Dal Mas, 2006.

The government's 2002-2006 strategic plan emphasises the importance of care and treatment for all those in advanced stages of HIV infection and AIDS. However, the total government health budget for 2003 was only US\$17 million a year, which makes it impossible for the state to provide anti-retroviral treatment. As at the start of the epidemic, it was the GHESKIO centres and Zanmi Lasante who took the lead in offering ART. Zanmi Lasante began to offer anti-retroviral drugs in its Cange clinic in 1998, and the success of this programme led to more funds being made available through the Global Health Fund, as well as through PEPFAR.

The money has been used to provide comprehensive treatment programmes, and has also helped improve the public health infrastructure. By the end of 2004, it was estimated that some 3,000 patients were receiving ART, out of almost 43,000 in need. This was less than half the target number of people on treatment that the government had outlined in its national HIV/AIDS strategy for 2002-2006. This failure to meet the targets must be set against the political turmoil which has virtually paralysed the country since 2003 and further weakened the capacity of both public and NGO health efforts.

In its 2004 *Summary Country Profile for HIV/AIDS* the World Health Organisation sums up the major challenges for AIDS treatment in Haiti in the following terms (PAHO/WHO 2004, p1):

Treatment is incompletely integrated into the existing health system and services, especially in tuberculosis and antenatal settings. The various initiatives and activities related to care need to be coordinated better. Tools, treatment protocols and models of service delivery are not standardised. Access to voluntary counselling and testing services is limited, especially among pregnant women and youth in high-prevalence areas. HIV/AIDS care and management has insufficient qualified human resources. The comprehensive supply management of drugs and diagnostics is fragmented. Monitoring and evaluation systems urgently need to be strengthened.

9: Stigma and discrimination

Modlyn Alphonse: from Wanament on the Haiti-Dominican Republic border

The clinic told me not to talk to anyone about this, because people are afraid of people with AIDS. They could humiliate me and even blackmail me, dominate me. People would not shake my hand, would not eat with me. They would cast me aside.

A lot of people have hang-ups about this. They have no information about the nature of this illness and so they discriminate against and stigmatise those who are ill or who they suspect of being ill.

Every time I go to the hospital I stop to look at a poster where there is a woman with AIDS and all her family are hugging her. I would like it very much if the reality was such as this poster makes out.

Interview by Gianni Dal Mas, 2006. Modlyn Alphonse is not her real name.

Despite the efforts of government, NGOs and the churches, all social sectors in Haiti remain enormously reluctant to talk openly about HIV and AIDS. There is anecdotal evidence that families reject relatives who have contracted HIV or developed AIDS. This is further complicated by the belief among many Haitians, in the poorest rural areas in particular, that the illness comes from supernatural causes and cannot be treated. There is also a widespread reluctance to talk about HIV and AIDS because of the negative consequences of admitting the infection in public. Few Haitians would mention the fact that they were HIV positive in the workplace, for fear of losing their job.

Saint Just Hillaire: from Port-au-Prince

I had two tests. When the first one came out positive, I didn't want to believe it was true. I was afraid: I thought for a long time about what was going to happen to my life. Fifteen days went by before I had another test, during which I tried to live normally, as if nothing had happened. No-one knew about it. I kept the secret for a couple of weeks. When I found out the result of the second test, I wanted to cry but I didn't. I was done for. The person who gave me the result did it arrogantly, telling me that I had very little time to live. He was very hard. I didn't know where to turn.

Up to now I haven't told anybody – well, nobody apart from the people who work in the care centre with persons living with HIV and AIDS. And there was a time, at the beginning, when I was afraid to go to the centre because someone could see me and think that I had the virus. Now I realise that it is the only place where I can find real help, so I can't be afraid of it.

In Haiti there is a lot of discrimination and stigmatisation of infected persons. Normally, when you rent someone's house, if that person comes to know your HIV status, they will quickly throw you out of the house or do something to make you leave quickly. But before doing that, they will tell everyone in the neighbourhood or zone of the city that you have the HIV virus, so that no-one will rent you another house.

The people who know you are ill, if they have no correct information about the illness, are frightened of you, avoid you, cross over to the other side so as not to pass near you. They no longer shake you by the hand.

Now, I have work that is not secure – if my boss knew that I was HIV positive, he wouldn't give me any more work. I can't run the risk of people knowing about my illness. If the owner of the house where I live were to throw me out, I wouldn't have money to begin to pay for another. And as I am ill I need to eat well, drink well. So the actual situation in Haiti obliges me to keep this secret, if I want to go on living in this

society of discrimination and stigma.

Even my closest friends, many of them discriminate against those who have HIV or AIDS, or at least say that you have to avoid such people, not talk to them, not touch them, not eat with them. They don't know that I myself have the illness, but I feel that this touches me inside, it hurts me very much. So I am more convinced than ever that I have to keep the secret.

Not even my family know or suspect anything. For them nothing has happened. I have suffered alone, inside.

Interview by Gianni Dal Mas, 2006. Saint Just Hillaire is not his real name.

Gerdy Alexis: social worker with Aprosifa, an NGO working in Carrefour-Feuilles, Port-au-Prince

Aprosifa works on two levels: the clinical and the community. We distribute condoms and pamphlets about prevention, and we have educators who work both in the clinic and in the community. We teach condom usage and have videos and discussion groups. Youth is a primary target group. We work with pastors, teachers, in barber shops and hairdressers, with voodoo priests and middle-aged women.

I run a group which initially started off with 20 women who had HIV or AIDS, but six have died. This is because Aprosifa does not have a licence to dispense anti-retrovirals. We only have AZT, and most patients also get multivitamins.

The women get together to talk about their situation. There is massive discrimination against them. They feel shame and have no-one except other women in the group to share their situation with. They can't tell their families because of the shame and stigma: only one out of the original 20 has told her family. One woman who died two months ago wanted me to tell her children, as she couldn't. Most of the women are single parents, so life is hard and they have to work hard to survive. They have little time to look after themselves. Hopefully the taboo will change one day, and people will be able to face reality and be able to go public about their illness.

Interview by Anne Street, 2004.

Liony Accelus: social worker for Promoteurs Objectif Zerosida (POZ)

The only person I told was my sister, because it was she who had sent me to the laboratory. After a time, when I began to see that thanks to the medication, HIV-positive people could go on living an almost normal life, then I began to talk with a group of my most intimate friends – they were my friends and I knew that it would remain a secret amongst ourselves. I told them that it was really because of HIV that I had got so thin, to the point that my face was not recognisable. What had been whispered for some time was the truth.

But I didn't have the courage to tell my wife. After I had been taking the medication for two months, I began to get stronger and put on weight. My sister told me that I had to talk to my wife and tell her that I had the illness: that in the end it was she who would decide whether to leave me or go on living with me. Although I understood what my sister was saying, I didn't have the courage to do it. I told her that it was she who should tell my wife, until she finally did it in March 2003.

At first my family and close friends thought that even with the medication I wouldn't last much longer. Then they saw me put on the pounds I had lost and they realised that the anti-retrovirals allow a person not to die from AIDS. So they decided to have the test themselves: the first was my other sister and a brother, then my friends. I know that at least three of them have tested HIV positive. I sent them to the offices where they could find good advice and they are still thanking me for what I did: having had the test very early, they do not need to take the anti-retrovirals, less strong medicines are enough.

I have often heard my own friends say that I shouldn't speak of AIDS in public, because it is a dirty and shameful thing. First I make them understand that AIDS is a

reality and that we have to understand it and know it well: we have to enter into this reality.

Finally I became involved in the work of prevention and witness to the other people in the neighbourhood and the city, so that they could know the virus and protect themselves. In general, finding that I am ill has made me reflect not only on my condition, but also on that of the other sick people all over the country. I have to tell people that AIDS exists because I know that in that way I can save many lives.

I think that lack of access to information is the first beginning of discrimination against persons living with the HIV virus. And I think too that we the infected are the ones who have to sensitise those who haven't got it yet: so that they learn how to protect themselves and at the same time how to respect us too.

On the social level, the information and sensitising campaign on HIV and AIDS has to continue with greater force. The theme of the virus has to be treated like something evangelical, sitting down together to discuss, know and analyse the problems. It will have to be a house-to-house thing.

The day after the interview with Liony, his wife commented:

I think that discrimination in Haiti is something difficult to change. What Liony is trying to do I think is necessary, but it will be many years before the situation really changes. If I think of Liony's friends, I think that not all of them have accepted him as ill with AIDS. I think that many of them treat him well when he is with them, but behind his back they say other things, they reject him too.

Interviews by Gianni Dal Mas, 2006.

10: People Living with HIV and AIDS (PLHA) associations

Despite the fear of stigma among families and a fear of reprisals at work, several associations of people living with AIDS have been formed in Haiti. These groups press constantly for greater public awareness of HIV and AIDS, more effective use of anti-retrovirals and other drug treatments, and respect for their rights. Many PLHA groups are small, but recently there have been greater attempts at coordination.

One such is the Network of PLHA Associations which includes seven organisations with a combined membership of over 4,500. The associations have each elected a member to represent them on the 'Platform of PLHA Organisations'. This has been set up with support from UNAIDS to lead advocacy and lobbying initiatives at a national level. The member groups range from regionally based groups to a network of men who have sex with men. About 70-80 per cent of the members of these organisations are women.

Besides addressing issues of care and treatment, the primary advocacy aim of the Platform is to address stigma and discrimination. It collects evidence of stigma and discrimination, including cases of violence, and these are printed each week in one of the national newspapers. The Platform is very active and forward-looking, but risks being swamped by the multiplicity of international donors who want to fund HIV and AIDS work in Haiti (Stredwick 2005).

Another dynamic PLHA group is led by Esther Boucicaut. Infected by her husband, who later died of AIDS-related illnesses, she was the first woman to admit publicly that she was HIV positive. Her example has been extremely influential in persuading other people living with HIV and AIDS to group together. 'I'm not going to let the HIV infection kill me,' she told participants at a symposium in 2005 organised by the Medical Faculty of the Catholic University of Haiti. Madame Boucicaut has also played a leading role in creating and facilitating self-help groups among PLHA. These groups now participate more actively in community health initiatives and undertake advocacy work on behalf of PLHA and their rights.

Jean Saurel Beaujour: executive director of the Association for National Solidarity (ASON), a PLHA organisation

Ever since ASON was set up in 1993, we have been advocating for HIV/AIDS patients to have access to medicines as is stipulated under the Haitian constitution. The biggest challenges are prevention and treatment of the disease. If I can have care, it means I am not going to be discriminated [against]; it means my rights will no longer be violated. That means that if I work somewhere and receive proper care, people will not discriminate [against] me. It also means that if I meet all the conditions to travel, I will not be impeded from doing so. If I ask for a job for which I am qualified, it will be offered to me. It means my rights are respected.

Interview by Calixte Clérismé, 2003.

11: Religious groups

Reverend Brunet Chérisol: Episcopalian minister and director of the NGO Childcare

If one of the church's priorities is to lead people's souls to heaven, it is not always obvious in Haiti that another should be to fight against HIV and AIDS. The hierarchy of the church has not yet felt the need to get involved. The question of vulnerability to the disease and how to reduce that has been confronted more by social organisations linked to the church and by certain individuals rather than by the church as a whole.

The most important challenges in the fight against HIV and AIDS are to combat poverty and the stigma of having the disease. As soon as the church no longer regards AIDS as a sin, the amount of stigmatisation of sufferers diminishes. The church still needs to educate itself about the disease, and to step up its efforts to educate and inform others.

Interview by Calixte Clérismé, 2003.

The established religions in Haiti were slow to rise to the challenge posed by HIV and AIDS, but in recent years have become increasingly committed to efforts to inform and educate their followers about the facts of the disease.

In January 2003, the Catholic Church of Haiti held its first National Conference on AIDS. The conference agreed:

- to give well-informed information about HIV and AIDS and the preventive methods encouraged by the church
- to participate in efforts to ensure that the rights of people living with HIV and AIDS were respected
- to continue to support those infected and affected by HIV and AIDS, in particular children orphaned by the disease
- to improve and make more available care in Catholic health centres
- to elaborate a five-year action plan.

Internationally, many Catholic organisations have contributed directly or indirectly to combating HIV and AIDS in Haiti. The Catholic development agency Caritas aims to help promote education and human rights awareness in the Haitian countryside, and by so doing to reduce the social stigma associated with HIV and AIDS. It also presses for greater access to effective treatment, as well as developing skills training and schemes to generate income to make PLHA more self-reliant.

The Protestant churches have taken the lead in training 1,700 pastors in techniques for counselling young people on HIV and AIDS. The churches, together with World Relief, also plan to set up anti-AIDS brigades which will aim to encourage young people to postpone their first sexual relationship, and to have fewer sexual partners.

Another encouraging development has been a new willingness on the part of the different churches to work together on HIV and AIDS and to coordinate their efforts.

Dr Paul Farmer: founder of Zanmi Lasante

Religious organisations should use AIDS as a way of re-thinking their priorities, and ask themselves some hard questions at the leadership level and at the lay level. For example, do we think it's acceptable for millions of Africans to die of AIDS without ever being treated? Do we think it's acceptable for there to be discrimination against people living with HIV? Do we think it's acceptable for children with HIV disease to be in school but not to have access to care? Do we think it's acceptable that some children are so poor they have to sell themselves to get to school or to stay in school? Let the

religious communities think about those kinds of thing. That would be my advice, to take a hard look at that.

I could use different language and say, if you want to think about churches and human rights, think about the rights of poor people. Some people call those social and economic rights: the right to access to care, the right to health care, the right to housing, etc. I think it would be good for churches and religious institutions to think about that. And, you know, a lot of other people are talking about sexuality and religious institutions. So that's discussed a lot and what is not discussed is the rights of poor people.

Interview by Calixte Clérismé, 2003.

12: Traditional medicine and voodoo beliefs

Traditional medicine, practised by healers who have no western-style qualifications but great local knowledge, is widespread in Haiti. It is often but not always linked to the religious beliefs of the voodoo system, which has been an important element in Haitian culture and everyday life since the 18th century. A study by the Panamerican Health Organisation (PAHO) in 2003 reported that 'between 70 and 90 per cent of Haitians generally turn to traditional medicine due to the lack of a health system, the low cost of this kind of medicine, and because of their beliefs' (PAHO/WHO 2004, p3).

Health workers trained in the western system said that two thirds of the people coming to see them for a consultation had previously been to a traditional healer. They were doubtful about the effects of these traditional methods, but the patients themselves had no doubts that they were effective and did not have secondary effects (Clérismé, Antoine and Lyberal 2003, p2).

The PAHO report also spoke of the advisability of combining efforts in the fight against HIV and AIDS with these traditional healers, and in particular with the *houngans*, or voodoo priests. The problem, as this and other studies suggest, is that many *houngans* and voodoo followers do not accept that illness has a direct link with behaviour or infection. According to voodoo beliefs, an illness such as AIDS is caused by a spell either from another person or from the spirits of the ancestors. There is also a belief that an injection can lead to death, and a lack of belief in the efficacy of western drugs.

Some *houngan* practices do put both the *houngans* and their followers or clients at risk of contracting HIV: for example, rituals which involve the exchange of blood or the use of unsterile equipment. There is also a relatively high level of sexual activity between *houngans* and others, both men and women, which is perceived as an honour for those involved and a means of enhancing the *houngan's* power. Older priests, or those who live in remoter rural areas with little access to information, are more likely to be resistant to changing their practices or referring clients to health services. This can lead to mutual suspicion and conflict between the voodoo *houngans* and local health providers such as state-run clinics or those run by NGOs or missions (Stredwick 2005).

On the other hand, *houngans* and other traditional healers tend to deal with their patients holistically, considering all the factors in their lives that might have contributed to their symptoms, and to that extent their care is more personal than that offered by curative health facilities.

Under the Aristide government, voodoo was recognised as a set of religious beliefs as valid as Christianity or other organised religions. At the same time, efforts were made to persuade *houngans* to join in the fight against HIV and AIDS, in a way that would not offend or challenge their beliefs.

Madame Mirlène Joanis: director of the Voodoo Believers' Association

As believers in voodoo, we have to struggle to get a socially responsible message about AIDS across. We have to accept the scientific view of the illness, and not speculate that it might have been produced by magic, and that there could be a miraculous cure. We also have to look at the polygamy of voodoo people, and tell them as strongly as possible they should use the condom. We need to instruct voodoo believers in questions of human and social and political rights, and that includes sexually transmitted diseases. So in my association we use the drums and the voodoo temples

to get people together, and then instead of holding a voodoo ceremony we show films or slide shows about the disease, we hand out pamphlets and condoms, we try to talk about it. And if any of our believers comes to us and says they think they have the illness, we make sure they go to a hospital. I don't think the main problem is an economic one, it's getting people to change their behaviour. People who have no economic problems also still refuse to change their behaviour. Lots of people know that the illness exists, but they still take risks. It's a question of habit, and habits are very difficult to change.

Interview with Calixte Clérismé, 2003.

13: HIV and AIDS and the Dominican Republic

Thousands of Haitian migrant workers cross the border into the Dominican Republic each year. About 500,000 Haitians and their descendants live in the neighbouring republic, many of them in terrible conditions in what are known as *bateyes* or shanty towns around sugar plantations. The rate of HIV infection among these people is much higher than in the rest of the Dominican population. According to UNAIDS, the overall AIDS prevalence rate in the Dominican Republic is 2.3 per cent, whereas in the *bateyes* it is more than five per cent (Batey Relief Alliance 2005, p1). This higher percentage has meant that the Haitian migrant workers often find they are discriminated against and denied access to health care because they do not have the proper official documents.

For historical reasons, the inhabitants of the two countries have regarded each other with suspicion and seek to affirm their different culture and traditions. But now a collaborative effort to fight the HIV and AIDS epidemic has become essential. Ulrick Gaillard of the Batey Relief Alliance said at a symposium on 'The Realities of HIV/AIDS in the Dominican Republic and Haiti' in 2005: 'the two populations are much closer than they think when dealing with commerce or migration. The cross-border mobilisation alone is ground for a swift response with a serious binational effort for HIV/AIDS prevention and control' (Batey Relief Alliance 2005, p1).

The symposium concluded that a huge amount remained to be done if these neighbouring countries wanted to work together to continue to reduce the incidence of HIV and AIDS. Among their recommendations were better surveillance and testing on larger groups in both countries; the empowerment of women and continuing efforts to promote awareness of the rights of PLHA; and a continuing emphasis on the fact that poverty is at the root of the spread of the disease, especially because the desperate economic situation of many women forces them into the sex trade.

14: Conclusions

The Haitian government and international health agencies agree that the response to HIV and AIDS was organised relatively early, and that it succeeded in stabilising the situation. This made the epidemiology of AIDS closer to that of the western world than that of many African countries. But Haiti and the Dominican Republic still account for more than eight out of 10 reported HIV and AIDS cases in the Caribbean, which suggests that there is no room for complacency.

This is particularly true given the chaotic political and social situation of Haiti in 2004-2005. One government was overthrown, and the authorities brought in to pave the way for fresh elections struggled to govern. The breakdown in law and order in many parts of the country severely undermined the state's ability to implement its plans for prevention and treatment. It also hindered campaigns to educate people to avoid high-risk behaviour and to use condoms.

The increasingly common outbreaks of violence have seen a disturbing increase in the use of rape as a weapon, leading to further concerns about an upsurge in the incidence of HIV and AIDS and other sexually transmitted diseases. In the violent social and political climate, the rights of PLHA have been set aside. Moreover, the violence and political uncertainty has not only reduced the revenues available for government health programmes, but has led to a further outflow of doctors, nurses and other health professionals.

The theme underlying this report is not simply HIV and AIDS, but poverty: the deep, grinding poverty that is the daily lot of millions of people in Haiti, struggling to survive without the resources to buy the basics they need to feed and clothe their families. Many have little or no access to education or information about measures to protect themselves. Lack of information may also mean that people fail to identify their status early, or cannot seek adequate treatment.

In the absence of adequate health care provision in Haiti, when HIV strikes the poor have nothing to fall back on. Living on less than US\$400 a year, millions of Haitians have no money at all to pay for treatment, or even for transport to a health centre. The lack of even the most basic services increases the incidence of opportunistic diseases, so that many more people die of AIDS-related illnesses than in developed countries. The logistics of accessing treatment in Haiti also work against the poor. Until 2004 only two centres in the country administered anti-retroviral drugs: one in downtown Port-au-Prince and the other on the central plateau. For those who live far from these centres, the challenge of travel is considerable.

Poverty and the lack of economic alternatives sometimes force women to earn money by selling sex, which puts them at risk of contracting HIV or other sexually transmitted infections. Often these women do not identify themselves as sex workers, so projects designed to target commercial sex workers fail to reach them.

At the national level, the government lacks the resources to address the situation adequately. Although over the years successive governments have fought to stem the tidal wave of HIV and AIDS, they have simply lacked the money to do so. The 2002 grant of US\$67 million over five years from the UN Global Fund, combined with money from PEPFAR, is encouraging. But the challenge for the government is to achieve effective collaboration between all the national, international and local players.

The government that replaced the transitional government in May 2006 must build on previous work and make HIV and AIDS a national priority. It needs to work closely not only with international donors but NGOs, the church and community organisations to improve prevention, treatment and care programmes. But above all it needs to address the underlying issues of poverty and injustice that make people in Haiti so vulnerable to HIV infection.

References

- Arthur, C (2001) *Haiti in focus*, Latin America Bureau, London.
- Batey Relief Alliance (2005) *HIV/AIDS in the Dominican Republic and Haiti: A bilateral challenge*, report on the Batey Relief Alliance's Third International Conference, April 2005.
- Clérisimé, C, Antoine, J R and Lyberal, J (2003) *Etude sur la situation de la médecine traditionnelle en Haiti*, Pan-American Health Organisation.
- Dubois, L (2004) *Avengers of the new world: The story of the Haitian revolution*, Harvard University Press, Harvard.
- Farmer, P (1992) *AIDS and Accusation*, University of California Press, Berkeley.
- Farmer, P (2003) *The uses of Haiti*, Common Courage Press, Monroe, Maine.
- Ferguson, J (1987) *Papa Doc, Baby Doc: Haiti and the Duvaliers*, Blackwell, Oxford.
- Ministère de la Santé Publique et de la Population (2002) *Plan stratégique nationale pour la prévention et le contrôle des IST et du VIH-SIDA en Haiti: 2002-2006*, Port-au-Prince.
- NCHR (1996) *Beyond the bateyes*, National Coalition for Haitian Rights, New York.
- NCHR (2000) *Restavek no more: eliminating child slavery in Haiti*, National Coalition for Human Rights, Port-au-Prince.
- PAHO/WHO (2004) *Summary country profile for HIV/AIDS treatment*, Pan-American Health Organisation/World Health Organisation, Washington DC.
- Ridgeway, J (ed) (1994) *The Haiti files: Decoding the crisis*, Essential Books, Washington DC.
- Stredwick, R (2005) *HIV Unit trip report for Haiti*, Christian Aid, London, June 2005.
- Street, A (2004) *Haiti 2004: A nation in crisis*, CIIR, London.
- UNAIDS/WHO (2002) *Epidemiological fact sheets on HIV/AIDS and sexually transmitted infections*, 2002 update.
- UNAIDS/WHO (2004) *Epidemiological fact sheets on HIV/AIDS and sexually transmitted infections*, 2004 update.
- UNDP (2004) *Human Development Report 2004*, United Nations Development Programme, New York.
- UNDP (2005) *Human Development Report 2005*, United Nations Development Programme, New York.
- WHO (2004) *Summary country profile for HIV/AIDS treatment scale-up, Haiti*, World Health Organisation, Washington DC.

PROGRESSIO

CHANGING MINDS ● CHANGING LIVES

Published January 2008 by Progressio
Unit 3, Canonbury Yard
190a New North Road
London N1 7BJ, UK
www.progressio.org.uk

Progressio is the working name of the Catholic Institute for International Relations, registered in the UK as a charity (number 294329) and a company (number 2002500).

© Progressio 2008

ISBN-10: 1-85287-325-6

ISBN-13: 978-1-85287-325-7

Nick Caistor, Jean Hugues Henrys and Anne Street assert their right under the Copyright, Designs and Patents Act 1988 to be identified as the authors of this work.

A catalogue record for this book is available from the British Library.

Progressio gratefully acknowledges funding from Trócaire and Christian Aid for this publication.

Cover photo: Passengers on a lorry, Wanament, Haiti. Photo: Nick Sireau/Progressio.

Design: Twenty-Five Educational