

NGO perspectives on access to HIV-related drugs in 13 Latin American and Caribbean countries



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This report is dedicated to the memory of Rubén Pérez Silva, founder and director of Acción Humana por la Comunidad, A.C. in Mexico and a tireless fighter against the HIV/AIDS epidemic. Rubén Pérez Silva died in December 1997 at the age of 39 from pneumonia related to HIV.



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Introduction

*NGO activities
to improve access
to HIV-related care.*

This document is based on reports supplied at the request of UNAIDS from 13 countries in Latin America and the Caribbean. The countries are Argentina, Brazil, Chile, Colombia, Costa Rica, Dominican Republic, Guatemala, Haiti, Jamaica, Mexico, Peru, Puerto Rico, and Venezuela. The purpose of the review was twofold: (i) to take stock of existing NGO activities and collaboration aimed at improving access to HIV-related drugs and (ii) to facilitate networking and partnerships in the region for the purpose of improving access to care for persons living with HIV/AIDS. Persons familiar with nongovernmental organizations (NGOs) in these countries and with a knowledge of the situation of people living with HIV/AIDS were asked to prepare the reports. In particular, they were asked to look at the availability of treatment for people with AIDS in the national health system—which is the context for the involvement of NGOs in providing assistance (especially drugs) to persons with HIV/AIDS—and the extent to which collaborative networks play a role in this. This report does not therefore claim to be an impartial account of NGO activities aimed at ensuring the availability of drugs. Rather, it represents NGOs' perspectives on the situation in the 13 countries.

The aim of this document is to point out the most important ways in which NGOs concerned with HIV/AIDS and with the persons who have this infection in Latin America and the Caribbean help facilitate access to HIV-related drugs. During the XIth Conference on AIDS, the slogan “No

greed, access to all!” was heard. The immediate reason was that the new AIDS drugs, the protease inhibitors, had a high price. This does not, of course, mean that access to all other AIDS-related drugs was easy. It was not, and it is not, especially for persons in developing countries. Thus, although lack of access to AIDS-related drugs is an old subject in developing countries, this topic aroused renewed interest when it affected developed countries. Access to treatment has become a global issue and has given rise to a new phase of global solidarity.

An examination of the country reports showed that, in most countries, advocacy for the rights of people living with HIV/AIDS are the predominant activities of AIDS NGOs in Latin America and the Caribbean. The NGOs speak out for equal treatment of people living with HIV/AIDS and ensure that People with AIDS are kept aware of their rights under the laws of the country. This approach is perhaps not surprising in view of the fact that large numbers of persons with HIV/AIDS in the region have difficulty accessing treatment for a variety of reasons. There is social prejudice against people with AIDS in a number of places and the cost of AIDS-related drugs is high.

A number of NGOs back up their advocacy activities with “activism” on behalf of persons with HIV/AIDS. Some have taken legal action against governments or insurance companies for not giving people with AIDS their rights. Others have denounced patent laws that they see as a means of maintaining high profits on HIV-related

drugs and thereby pricing them out of the reach of many who need them.

It is normally possible to obtain HIV-related drugs only through official routes such as health institutions and social security systems. In some cases, NGOs supply drugs to persons with HIV/AIDS, some have set up drug banks or community pharmacies. In other cases, NGOs have set up special "solidarity funds" to share costs in an attempt to enable persons with HIV/AIDS to purchase drugs. Other NGOs concentrate on providing information about the disease and about drugs for treating it, since many persons with HIV/AIDS simply do not know what is available and what could be the best to help them.

The role of NGOs in access to HIV-related drugs in Latin America and the Caribbean is evolving. The country reports submitted to UNAIDS do not reflect a static situation. The NGOs are themselves evolving as situations change. Since NGOs often come into being in order to meet a felt need within a population, new NGOs are appearing in Latin

America and the Caribbean and their impact has yet to be felt.

The country reports mention a variety of joint activities by groups of persons with HIV/AIDS. These are not the work of NGOs but cooperative actions by people trying to find common solutions to problems that they share. As such groups organize their activities more formally, new NGOs are born and make their unique contribution to the evolving picture described here.

This document aims to show what different NGOs, set up for a variety of purposes, are doing in different countries to improve access to HIV-related drugs¹. In spite of the changing picture and although it is not an exhaustive account, it is hoped that the experience that is put on record here will help foster collaborative efforts in Latin America and the Caribbean to improve access to appropriate treatment for persons living with HIV/AIDS.

(1)- The activities of NGOs have been outlined but the report does not necessarily mention the work of all NGOs. For instance, there is no mention of the work of the Red Cross, Médecins sans Frontières, GAPA, Lar Betania, Viva Cazusa or many other organizations which carry out these activities.

The context

*The social,
economic
and cultural
context of NGOs.*

As in many other fields of concern, the work of NGOs related to HIV/AIDS is often determined by other social, economic and cultural factors. Thus, in any given country, the number of persons with HIV/AIDS and drug sources such as public and private health institutions, social security systems and so on provide the context in which AIDS NGOs operate.

The country reports used in preparing this document present a variety of perspectives, stemming from different national situations and from the reporters'

particular points of view. The countries of Latin America and the Caribbean exhibit many differences. Several countries have undergone severe political crisis in recent years. There are sharp variations both between and within countries in socioeconomic status, as well as in the kind of health services offered to the population. There are also marked differences in the AIDS incidence rates and the accumulated AIDS numbers in countries (see Tables 1 and 2). Furthermore, the AIDS epidemic affects different countries and communities in very different ways,

for reasons that cannot be explained only in terms of economic status. The varying mix of public and private health care (and the interaction of these two) is part of the context, as is the variation in sources of drug supply.

Yet at the same time some common cultural and historical features of a number of countries in Latin America and the Caribbean, and also economic experiences and the influences of tourism, allow for some tentative comparisons and conclusions to be drawn. To some extent, the ways in which AIDS NGOs act in the region are similar, though emphases are different. Their work may have similar goals but also reflects the NGO tradition in the country, the type and structure of the health service (the balance of public and private services and their interaction), and even the influence of international funding agencies, both governmental and nongovernmental.

The local reports summarize the situation in each country with regard to access to treatment. The situations differ. Argentina and Brazil, for instance, show

access to antiretroviral therapy, including protease inhibitors, while Haiti does not provide drugs for tuberculosis. Colombia is beginning to provide antiretrovirals and other nations are doing the same as patients take legal action against governments or social security systems. The presence of NGO activism has been essential to achieving and expanding access and to making a reality of the right to health and life that is guaranteed in so many Constitutions and laws in the region.

Growing networks of people living with HIV/AIDS are also important to the context. Since 1995, networks have been created in Brazil, Chile, Colombia, Costa Rica, Mexico and Venezuela, and Jamaican and Dominican chapters have been added to the Caribbean network. There is also growing interaction between groups of people living with HIV/AIDS in Costa Rica, Guatemala and Panama. The possibility of having treatment is an stimulus for these networks. A slogan used by people living with HIV/AIDS in Mexico is "Antiretrovirals and quality of life for everyone!"

NGOs involved in AIDS care

There are many different types of NGOs.

Many of the NGOs with work related to HIV/AIDS and to people living with HIV/AIDS in Latin America and the Caribbean are groups that originally provided humanitarian, legal or some other kind of assistance and have expanded the scope of their work as AIDS has become a greater cause for concern. Of course, a large number of the present NGOs offering assistance in the area of AIDS were created specifically for that purpose. While the region has many types of NGOs involved in

AIDS activities, the activities of three kinds are common to a number of countries.

People with HIV/AIDS

Throughout Latin America and the Caribbean, the activities of groups of persons with HIV/AIDS are having an increasing impact on society's attitudes to persons with this disease and on their access to treatment.

● In **Chile**, for instance, the Coordinadora Nacional de Personas Viviendo con el VIH (COORNAVIH) was formed in August, 1997. It arose out of efforts by patients' organizations in several of the main hospitals in Santiago and it claims to represent the interests of people living with HIV/AIDS nationally. It advocates for treatments and services, leaving direct provision of services to other groups. Centro de Apoyo a las Personas con el VIH (CAP-VIH) was formed in 1994 and is the oldest continuous grouping. Corporación Chilena de Prevención del SIDA (CChPS) has a committee made up exclusively of persons living with HIV/AIDS.

● In **Colombia**, self-help groups of people living with HIV/AIDS have made a significant mark by advocating for their right to treatment. There was no movement of people living with HIV/AIDS in the Dominican Republic until very recently but now that country has followed the lead of others and such a group has been established with access to drugs as one of its main objectives.

People living with HIV/AIDS are also playing a growing role in the campaign for access to treatment in Mexico. The first meeting of people living with HIV/AIDS in Mexico, which was held in Mexico City in November 1995, led to the establishment of a national network for people living with HIV/AIDS that has gone from strength to strength.

● The **Dominican Republic** and **Jamaica** report the importance of the Caribbean Network of People Living with HIV/AIDS (CRN+) and its local chapters. Meetings of national networks of people living with HIV/AIDS have been held in different countries. In 1996–1997, such meetings took place in Brazil, Chile, Costa Rica, Mexico and Venezuela. Peru has developed network of self-help groups called GAMS (Grupos de Ayuda Mutua).

Homosexual groups

Homosexual groups were among the earliest NGOs to work with AIDS-related issues. In both **Mexico** and **Peru**, for instance, gay groups were the first to alert society to the dangers of AIDS and to the need to take preventive and protective measures. Now, throughout the region, lesbians and gays continue to be very active with regard to access to treatment.

● In **Costa Rica**, Triángulo Rosa—a support group for lesbians and gays—has been one of the driving forces in the campaign for the rights of people living with HIV/AIDS. It is one of the leading organizations in the patients' coalition that is directly concerned with obtaining access to HIV-related drugs for persons with HIV/AIDS.

● In **Guatemala**, the Organización de Apoyo a una Sexualidad Integral frente al SIDA (OASIS) is the only organization for lesbians and gays. It has counselling services for people living with HIV/AIDS and has recently spoken out for their rights, including the right to access to health care. It organized a candlelight vigil, together with groups of people living with HIV/AIDS, in one of the main squares of Guatemala City in 1996. OASIS also helped organize a human rights colloquium on sexual minorities and people living with HIV/AIDS.

● **Jamaica** also has active lesbians and gays, as do other Caribbean islands. Their role in promoting access to HIV-related drugs for people with HIV/AIDS is seen as a growing one. It is suggested that the efforts of CRN+ and the Caribbean Forum of Lesbians, All-sexuals and Gays (C-FLAG) may be important in this regard. Homosexual groups have also made a contribution to access to treatment in Chile and Peru.

Church-related NGOs and institutions

The contribution of church-related NGOs is considerable in terms of providing assistance of various kinds to people living with HIV/AIDS. In Brazil, for instance, some NGOs with AIDS activities in the State of São Paulo are linked to the Roman Catholic Church; these organizations provide 250 beds for AIDS-related cases in hospices. In Chile, Catholic groups, including an order of nuns, maintain clinics and homes for people with advanced AIDS. Also in Chile, the Lutheran Church is involved in AIDS-related work through its Popular Health Education project. And in Colombia the Eudes Foundation provides partial access to medicines for a limited number of patients.

- **Haiti** has a number of church-related institutions that provide medical assistance to persons with HIV/AIDS. The Hôpital St Croix de Léogane is a 120-bed church hospital that registers some 24 new HIV-positive cases monthly. As the background to this report was being prepared, the medical

director reported having on stock a one-time donation of 50,000 tablets of AZT (about six months supply) from an affiliated church in the USA.

Also in **Haiti**, the Hôpital des Petits Frères et Sœurs, which is run by Catholic nuns, provides care for disadvantaged children. Among the 1000 patients hospitalized last year, 120 were HIV-positive. In addition, the 80-bed Hôpital de Fermathe, which is affiliated with the Baptist Church, provides services for tuberculosis patients, for people with HIV/AIDS and for their families.

It is reported that church groups play a vital role in Jamaica by providing primary health care through their clinics. Food for the Poor International (A Roman Catholic group) is particularly active in making essential HIV medications available to poor people through its clinic in downtown Kingston.

Other NGOs in the region which provide medical care and monitor treatments are Médecins sans Frontières, Medicus Mundi and the Red Cross.

Types of NGO activity

Country-specific forms of advocacy.

Advocacy

Advocacy by AIDS NGOs in Latin America takes a variety of forms. Much is, of course, directed to improving the overall rights and conditions of people living with HIV/AIDS, though some actions have been directly focused on access to HIV-related drugs.

- In **Argentina**, more than 50 NGOs that report doing HIV/AIDS work or conducting related programmes have been officially registered. Some have tried to replicate lobby or advocacy models that

worked in North America or Europe, but with limited success. There is now growing cooperation among peer organizations and with neighbouring countries to work out more appropriate advocacy strategies.

- In July 1997, **Brazil** had 520 organizations that had some work related to AIDS. Popular advocacy strategies include participation in forums and commissions such as the State Commission on AIDS. Relations with the media are used to seek visibility for the concerns of AIDS NGOs, and NGOs have also backed street demonstrations to protest the lack of medi-

cations in public health services. NGOs are constantly monitoring the situation with regard to the availability of HIV-related drugs and the rights of persons with an illness to appropriate medical treatment. Two bulletins are published by NGOs to provide information on AIDS treatments.

Political activism and defence of the rights of people living with HIV/AIDS have been successful advocacy strategies in Colombia. The country has some 60 NGOs working in the area of AIDS though less than 10% have policies on access to medicines. Various types of advocacy and legal action combined with political determination have achieved new AIDS legislation. In the late 1980s, NGOs such as the Liga Colombiana de Lucha contra el SIDA (LCLCS) and FIASAR, and self-help groups such as Acción Por Vida and others, participated in drawing up the Decree Law 559 which came into force in 1991. In 1995, NGOs and self-help groups at the Second National Symposium for Human Rights and HIV/AIDS decided to petition the Ministry of Health for the modification of this law. During 1996 and 1997 a media campaign (television, radio, newspapers) was carried out in support of this. In 1996 NGOs were involved with the Ministry of Health in the final modification. The modified law became the national AIDS legislation that has been in use in Colombia since the beginning of 1997. Antiretrovirals (reverse transcriptase inhibitors and protease inhibitors) are included in the list of medicines that, according to the new law, people living with HIV/AIDS in Colombia have the right to receive within the national health care system.

In January 1995 at the Conference for Strategic Planning of Resources for NGOs Working with AIDS in Latin America and the Caribbean, the First Lady of Colombia spoke about the two fundamental pro-

blems for people living with HIV/AIDS - access to medicines and violation of human rights. During the inaugural ceremony of the conference, the First Lady announced the formation of the National Medicine Fund for High Social Impact Diseases (AIDS, cancer, haemophilia). The aim of the fund is to make medicines accessible to persons with limited financial resources through NGOs and other institutions that receive subsidies for the purchase of medicines. A number of new NGOs appeared in 1997 that include access to medicines in their philosophies.

● Advocacy in **Costa Rica** has involved both lobbying of decision-makers and more general publicity about the campaign for better access to HIV-related drugs. During 1996 a commission of Costa Rica's Legislative Assembly, working with representatives of NGOs, prepared a draft law designed to combat discrimination against people living with HIV/AIDS. Triángulo Rosa, an organization that supports the homosexual population, and Fundación Vida, which provides a counselling service to persons people living with HIV/AIDS, have cooperated in the patients' coalition which began in 1997 to lobby the 52 representatives of the Legislative Assembly regarding access to HIV-related drugs.

Triángulo Rosa has also issued press releases in English and Spanish in Costa Rica. Several of these have resulted in articles about the campaign appearing in the local press. The country's largest newspaper, La Nación devoted the cover story of its Sunday magazine to a very thorough analysis of the campaign for access to HIV-related drugs. It was at this time that the coordinator of the patient empowerment programme of the patients' coalition publicly announced that he was HIV-positive. This marked quite a change for HIV-positive persons

because this was the first time anyone in Costa Rica had spoken out so openly in public about his HIV status. Articles and press releases have also appeared regularly in Internet and this has led to contacts with other patient groups on an international level, as well as a substantial donation. The patients' coalition is involved particularly in legal struggles for access to treatment for persons with HIV/AIDS.

- The **Dominican Republic** has a law governing the rights and duties of persons infected with HIV and of those who interact with them (i.e. employers, sexual partners, doctors, etc). The law includes penal and economic sanctions for those who break it. NGOs were involved in campaigning for the law and in the three years of debate and discussion that led up to it. Now that it is on the statute books, NGOs are trying to monitor its enforcement. To date, there have been only three legal suits presented by people with HIV, all regarding labour rights.

- In **Guatemala**, the Asociación Guatemalteca para la Prevención y Control del SIDA (AGPCS) has tried to exert pressure on the public health system to enable people with HIV/AIDS to receive appropriate antiretroviral treatment. People with HIV/AIDS have previously received alpha interferon as part of a clinical trial. However, currently some public institutions provide only drugs for prophylaxis of opportunistic infections while others provide a combination of three antiretrovirals. AGPCS has lobbied the national congress, the directors of San Juan de Dios hospital and the pharmaceutical companies to promote access to all existing medications for people with HIV/AIDS. In addition, the OASIS group for lesbians and gays has organized workshops that have included advocacy for the human rights of people living with HIV/AIDS and

sexual minorities, including the right to health care. OASIS also is one of the cofounders of the Asociación Regional Centroamericana de Gays y Lesbianas (ARCEGAL), which includes among its objectives the promotion of access to treatment for people with HIV/AIDS.

- In **Haiti**, a national forum between the Ministry of Health and NGOs, which was held in 1995, passed a number of resolutions. One of these recommends updating of the country's laws on several issues, including discrimination against people living with HIV/AIDS.

- A number of initiatives by people living with HIV/AIDS have recently emerged in **Mexico** with the aim of fighting for better health services. The Frente Nacional de Personas Afectadas por el VIH/SIDA is particularly concerned with access to drugs and medical services, while Red Mexicana de Personas que Viven con VIH/SIDA promotes the quality of life, networking, empowerment and the dissemination of treatment and health care information.

In 1991, the former NGO confederation "Mexicanos contra el SIDA" organized the first national meeting of AIDS service NGOs in Mexico. This was followed by the first national consultation on ethics, law, human rights and HIV/AIDS, with the participation of scientists, AIDS activists, NGOs and people living with HIV/AIDS. The NGO Amigos Contra el SIDA, the Asociación Mexicana de Servicios Asistenciales en VIH/SIDA and Centro de Investigación y Terapéutica Avanzada en Inmunodeficiencias (CITAID) have organized a symposium on "El SIDA Hoy" for the past two years with national and foreign speakers. ACASIDA, an NGO from Acapulco, also organized a similar symposium.

Amigos contra el SIDA, together with the National Commission on AIDS (CONASIDA) and the National Congress, has organized national AIDS meetings in Tapachula, Tijuana and Mexico City to inform and present proposals to decision-makers in different regions of the country. Other NGOs such as AVE de Mexico, Centro de Atención Profesional a Personas con SIDA (CAPPSSIDA), Acción Humana por la Comunidad and Fundación Mexicana de Lucha contra el SIDA, organize workshops on AIDS. In 1995, the first national meeting of people living with HIV/AIDS took place in Mexico City. This meeting of more than 100 people living with HIV/AIDS from throughout the country formed the basis for a national network of people living with HIV/AIDS.

Mexican NGOs are slowly building their communication channels and increasing their social and political presence. In the campaign for the election of the mayor of Mexico City, for instance, some NGOs held talks with all the candidates. Another important initiative is the Great Commission on HIV/AIDS, a forum that brings together representatives of both government and NGOs.

The Frente Nacional de Personas Afectadas por el VIH/SIDA or FRENPAVIH, was founded in 1996 with the aim of advocating for public policies that would improve the quality of health services in Mexico, both for people living with HIV/AIDS and for others. The objectives of this group specifically include access to all necessary drugs for persons with HIV/AIDS. FRENPAVIH organised weekly meetings and soon recruited 1000 persons willing to help with political advocacy. In November, 1996, representatives of FRENPAVIH and other NGOs had a meeting with the Minister of Health at which the minister presented a proposal for a drug fund.

A demonstration in April 1997 in front of the national medical centre protested the lack of drug supplies and called for the inclusion of protease inhibitors in the country's basic medicines catalogue. The demonstration stopped traffic in one of Mexico City's main streets and resulted in negotiations between representatives of FRENPAVIH and of the social security service which led to the setting up of a joint committee to look into the matter. The result has been that it is currently possible to have access to Saquinavir, Crixivan and 3TC through the normal social security service, although the medical criteria applied make it accessible only to people in a very advanced stage of the disease.

● Various advocacy activities in **Venezuela** have included lobbying the government to sign the Paris Declaration on AIDS, sending 5000 letters to the President, and lobbying for the inclusion of AIDS in the draft of a law on special illnesses. NGOs also lobbied for the inclusion of access to AIDS treatment in the final document of the Iberoamerican Summit of Presidents that was held in Venezuela in November 1997.

Also in Venezuela, Acción Ciudadana contra el SIDA (ACCSI) and Red Nacional en Derechos Humanos y SIDA has been active in advocacy work on behalf of people living with HIV/AIDS since 1994. This network has been expanded substantially and includes 13 federal bodies, as well as HIV service organizations and human rights organizations that include AIDS concerns in their programmes.

Legal action

In a number of countries in Latin America and the Caribbean, NGOs have expanded their advocacy efforts on behalf of people living with HIV/AIDS to include legal action. This varies from place to place according to what is feasible both in

terms of the law and in terms of the resources of the NGOs. The legal action falls into two main categories - that which is directed against the government to try to oblige it to provide access to HIV-related drugs for persons with HIV/AIDS, that which is directed at insurance companies to try to oblige them to pay for treatment and drugs.

Legal action regarding the government

- In **Argentina**, 3% of the salary of every legally employed person is withheld for union health care. A law was passed in 1995 requiring those unions to cover 100% of HIV treatment, including all procedures and tests. Private health systems, both prepaid and health insurance, are now also being required to cover a compulsory medical plan that includes HIV treatment and follow-up. The law is still being introduced, but coverage will be the same as for other drugs—i.e. 50% or 75% with the remaining costs to be paid by the patient. It is impossible to know at this point how the law will be implemented. In practice, 70% of private health companies cover HIV-positive clients who have been affiliated for some time—usually two years or longer. Unemployed persons, those without union health care coverage and those subject to social hardship can, in theory, be treated at public hospitals and obtain their medicines through the National AIDS Programme.

Argentina has no specific laws compelling the state to provide HIV treatments but health is considered a constitutional right. Some court actions were taken against the government in 1996. The state accepts its responsibility in this regard, although supplies are sometimes erratic. About 25% of those who qualify for these benefits are currently getting their medicines. The National AIDS Programme is

supposed to distribute drugs to provincial AIDS programmes. NGOs and minority/community groups have complained about the violation of laws and the government's lack of action. These efforts have played a role in obtaining the benefits that currently exist.

- In **Brazil**, the Ministry of Health began to supply antiretrovirals (AZT) in 1991. It declared in 1995 that it will supply AZT, ddI, ganciclovir, fluconazole, pentamidine, aciclovir and amphotericin B to those who need these drugs and in March 1996 a technical committee of the Ministry drew up guidelines for the use of antiretrovirals, including protease inhibitors. According to a law passed in 1996, HIV-related drugs should be provided free of charge by the federal, state and city authorities. This context provided the background for legal action that has been used as a way of obtaining access to medications. In São Paulo, for instance, one NGO took legal action that established the right of access to medication from the federal or state government for 2100 people. This action was based on articles of the Brazilian Constitution, which establishes the right to life and health. It was followed by similar actions by other NGOs and private lawyers. Finally, protease inhibitors began to be provided in December 1996. The Ministry proposed that state and city authorities should provide 30% of the costs of HIV-related drugs. Costs are high and NGOs report shortages in some interior regions as of September 1997 but the situation has improved and drug supply is now regular according to government sources.

- In **Chile**, the Constitution and laws do not guarantee health as a right but rather the “free [unobstructed] and equal access to government actions in prevention, promotion or recuperation”. However, the laws governing sexually transmit-

ted diseases provide for free treatment, and HIV is considered a sexually transmitted disease in the public health system. No one has yet legally challenged the selection of drugs made available, though the possibility has been discussed. In any case, Chilean law is not precedent-based; a victory for one patient would not necessarily create new conditions for everyone, even though the impact would certainly be considerable and might provoke a policy change.

- The first legal action regarding access to treatment in **Costa Rica** dates back to 1992, when an appeal was made by a lawyer on behalf of several patients to the Costa Rican Supreme Court demanding that the government provide AZT to people affected by HIV/AIDS. The appeal was denied when the judges ruled that there was not sufficient evidence that AZT would make a significant difference in the patients' lives, and that its cost was extremely high in terms of the benefits achieved. AZT was, however, provided to pregnant mothers, though only until they gave birth.

The Costa Rican government's social security fund decides which medications should be made available to patients. Until late 1997, none of the newer antiretroviral medications were provided. The drugs were available in the country but anyone wishing to have them had to buy them at the commercial price that was beyond the means of most AIDS-affected people.

In 1995 the patient coalition in Costa Rica began a campaign to pressure the government (i.e. its social security fund) to provide the new medications. The patient coalition requested assistance from the government-funded ombudsman agency that is enabled to advocate on behalf of any minority that feels that it is being discriminated against by the government. However, no progress was made.

In July 1997, the campaign took a different strategy when several patients appealed to the Supreme Court, claiming that the government was failing to provide medications that had been recommended by physicians. One of the patients was severely ill with a variety of opportunistic infections; his appeal stated that the social security fund had refused to supply him with the drugs AZT, 3TC and Crixivan that were recommended to him by two physicians.

The seriousness of this patient's condition led the court to treat the case with urgency and in September 1997, in spite of the social security fund's plea that supplying the drugs would cost US\$ 900 a month, the court decided in the patient's favour. It ruled that the social security fund should provide him with the drugs that had been medically recommended for his condition. Unfortunately the decision was too late to save him and he died three weeks later, but the decision encouraged other patients to prepare similar petitions.

By November 1997 the judges of Costa Rica's Supreme Court announced a decision that the social security fund should provide modern antiretroviral drugs to patients in need of them. The court acknowledged that the high cost of supplying such drugs would place the social security fund in an uncomfortable position, but stated that financial concerns could not take precedence over the right to life and health. In its ruling, the court affirmed that the provision of effective medical care for people affected by AIDS is an obligation of the state. As of April 1998, some 320 persons in Costa Rica were receiving AZT, 3TC and Crixivan via the government's social security fund.

- The first legal action regarding access to HIV-related drugs in **Colombia** was won in 1993 against a public health facility that was judged to have denied



medical attention and access to medicines to a person living with HIV/AIDS in the city of Villavicencio. This case attracted a great deal of attention in the media, but without preventing a repetition of the problem. The judgement in the kind of legal case that was brought relates only to the parties involved in that particular case and is not held to have a collective application. From 1994 to the present, many cases have been brought against the health care sector and businesses for violations of human rights. Legal actions regarding denial of access to medicines for people living with HIV/AIDS have been brought chiefly against the social security system and health agencies.

- NGOs in **Venezuela** are concerned that rapid political change (four different health ministers in three years) and economic difficulties have led to AIDS falling rather low on the list of health priorities. Public hospitals have not been able to supply HIV-related drugs, except for short-term protocols or donated drugs. As a result, legal actions against the Ministry of Health are being prepared by ACCSI.

In March 1997, a group of 30 persons with HIV/AIDS brought an appeal of protection against the social security system in Venezuela. This was accepted in all its parts and this decision guarantees full treatment to the claimants (including protease inhibitors and viral load). A second appeal has been launched by another group of 79 persons with HIV/AIDS.

Table 3 provides an overview of the countries with an explicit AIDS-related law, policy, decree or resolution.

Legal action regarding private insurance companies

- **Argentina** has a law that obliges private health insurance companies and

“obras sociales” (private but non-profit social security institutions) to provide AIDS treatment.

- **Brazil** has a specific law (9313, issued in 1996) on AIDS that requires the federal, state and city governments to supply the necessary medications for treatment. Legal action has been taken to obtain treatment through private health insurances; one NGO has brought more than 400 legal cases against private health insurances. The legal battle for the covering of all diseases by private health insurance companies resulted in Resolution 1401 of the Federal Council of Medicine in 1994 which requires all health providers to cover all the diseases described in the International Classification of Diseases. One hundred NGOs submitted a petition to the National Congress requesting that any legal regulation of health insurances should respect Resolution 1401 and two demonstrations were held in São Paulo in 1997 in support of the petition.

In the state of Rio de Janeiro, Brazil, two NGOs provide juridical assistance and present claims on behalf of their clients. Thirty-four such cases have been brought against health insurance companies so far. The 34 lawsuits are to the benefit of 231 patients. The number of these legal actions in Rio de Janeiro has gone down, probably because some health plans already offer assistance although their contracts exclude AIDS treatment, and some others offer assistance for a monthly fee larger than normal and with an initial waiting period longer than usual. New lawsuits tend to be brought on behalf of persons who need specific drugs for opportunistic infections, or new antiretrovirals that are not licensed in the country or not mentioned in the therapeutic guidelines of the Ministry of Health. The reduction in the number of legal cases regarding access to HIV-related drugs does not mean, therefore, that all

patients are receiving the medication they need. Many prefer to wait for the medication rather than to sue and some are not aware of the new therapeutic possibilities for treating their illness. In this respect, AIDS NGOs play an important role in providing information not only to patients but also sometimes to health services.

Patent laws

No direct legal action is reported regarding patent laws, but NGOs in a number of countries are clearly concerned about these laws and have raised their concerns vociferously. Some of the new HIV-related drugs are very expensive and their cost often seems astronomical when it has to be borne in full by a person with a low income. Several NGOs report the need for a much closer look at these laws which protect the patent of the developer of these drugs and forbid their manufacture by others. The effect of the laws is that the drugs can be obtained only from the source that developed them—usually a multinational company—which normally means that the price is high. The report from Jamaica, for instance, recommends that the transparency of patent laws in that country should be examined and that laws should be clarified with a view to reducing the cost of treatment.

● In **Argentina**, the national Constitution and other laws have been used as the basis for a ruling that people with HIV/AIDS have a right to treatment (in 95% of cases). Law in Argentina does not currently regulate patents and trademarks. This means that, for instance, eight different trademarks and presentations for AZT (zidovudine) can be found on the local market. However, Argentina is under strong pressure to pass a drug patents law. NGOs are waiting to see what the government decides but they estimate that the introduction of such a law would result in

an increase of about 30% in the prices of all medicines.

● **Brazil** approved a drug patent law in May 1996 which means that drugs under patent must be bought from the owner of the patent. In Brazil some local and public laboratories produce AZT, ddI, ddC and d4T. This results in lower prices and means that the funds used to purchase the drugs do not leave the country.

Drug supply

A number of NGOs in several countries are involved in drug supply to persons with HIV/AIDS. This kind of activity does not follow a standard pattern since the NGOs vary in type (from NGO hospitals to small groups of volunteers) and the situations in which they are working differ.

● In many countries of **Latin America** and the **Caribbean**, national NGOs have international contacts. Some are members of an international network, while others have enlisted helpers abroad through personal contacts and visits. In this way, many of the HIV-related drugs supplied by Latin American and Caribbean NGOs to persons with HIV/AIDS are purchased in or donated from the USA⁽²⁾.

● In **Argentina**, NGOs do not provide treatment for persons with HIV/AIDS but some have drug banks that enable persons with HIV/AIDS to continue their treatments when public supplies fail. One of them also has counselling and social work service that complete the formalities so that persons can obtain public benefits free of charge. The same NGO is currently offering training in diagnosis and treatment.

● In **Brazil**, the situation varies from region to region. In São Paulo, for instance, NGOs supply some 800 monthly doses, of which 200 at most are antiretro-

virals. The drugs are mainly donated, most of them by patients who have changed to other treatments, and some come from patients who have died. Some donations also come from pharmaceutical laboratories, some from abroad and some are purchased.

In Rio de Janeiro, Brazil, there are only a few irregular NGO initiatives for drug supply. A number of NGOs have, however, joined in an informal solidarity network whereby persons with HIV/AIDS share their drug supplies. The network does not supply drugs regularly since it has no regular supply itself but helps to fill gaps in the public supply. This solidarity network is particularly useful when public institutions run short of HIV-related drugs. The solidarity network relies on patients' donation, mainly from those who have changed treatment or died.



● In **Chile**, NGOs have focused on providing comfort and relief to the most destitute terminally ill. The Santa Clara Sisters, however, have stated that they will assure triple-drug therapy to all children with HIV in Chile. Meanwhile, the Laura Rodríguez Foundation in Chile has been running a drug bank for several years. The foundation signed an agreement with the Ministry of Health to import and distribute drugs. It buys the drugs in bulk to reduce costs. A month's supply of 3TC, for example, which sells commercially at US\$303 can be purchased through the foundation for US\$246. Approximately 85 patients use the programme, including 23 whose costs are covered partially or entirely by the foundation itself.

● In **Colombia**, a self-help group of people living with HIV/AIDS brings into the country medicines that are collected by friends abroad, generally in the USA. The Liga Colombiana de Lucha contra el SIDA also obtains medicinal donations

from abroad. It has a cost-sharing project that subsidizes 50–100% of the cost of treatments for people living with HIV/AIDS. Those with more financial resources help to subsidize the costs of those with little money. This project covers 100 patients, receives international support and has a subsidy from the National Medicine Fund. The Eudes foundation in Colombia has also obtained partial access to medicines for a number of patients through donations and through the support of the National Medicine Fund. However, it has not been able to reach total coverage of its patients. FUNDAMOR provides medicines for the treatment of HIV/AIDS in children in one city.

● In **Guatemala** the Asociación Guatemalteca para la Prevención y Control del SIDA (AGPCS) provides antituberculosis drugs, antibiotics (prophylactic and therapeutic), antifungal drugs and a number of HIV-related drugs. However, the association's supply of HIV-related drugs is not sufficient to treat the 170 patients seen each month at its outpatient clinic. Some 70–80% of the persons treated at the clinic are symptomatic and require treatment. The Roosevelt hospital's infectious disease clinic, which was part of AGPCS' projects until 1996, also provides some drugs for AIDS patients and supplies AZT to health care personnel who are exposed to HIV. Some 300 outpatients are seen each month at this clinic and 60% of them present with symptoms related to AIDS. Some therapy is provided as "compassionate care" to 15 AIDS patients, but the rest have to buy their drugs.

The Asociación para la Prevención y Ayuda a Pacientes con SIDA (APAES) in Guatemala gives various kinds of support to 180 people with HIV/AIDS, but it can provide antiretroviral drugs to only 15 of them. It provides antibiotics to all its

clients. APAES obtains small donations of drugs from individuals and drug companies but most antiretroviral drugs are obtained through personal contacts, mainly with the People with AIDS Coalition in Miami. The Hospicio Casa San José is Guatemala's only hospice for people with HIV/AIDS. It provides antibiotics and other drugs but has no antiretroviral drugs. Between 15 and 20 people receive care each month. The hospice receives drug donations from the United Kingdom.

- Supplies of HIV-related drugs are uncertain in **Haiti**. PROMESS (Programme des Médicaments Essentiels) is a new programme established by the Ministry of Health to ensure the availability of basic drugs and contraceptive methods in rural health centres. The PROMESS programme, which is being carried out with overseas funding and with assistance from the Pan American Health Organization, supplies essential drugs in bulk at low prices from its main warehouse and from several subsidiary depots. Almost all NGOs have access to PROMESS which stocks six drugs suitable for persons with HIV/AIDS. Sometimes, however, supplies are not available and NGOs have to get them at much higher prices through private suppliers.

- In **Jamaica**, Centre for HIV/ AIDS Research, Education and Services (CHARES) is a registered NGO that was started in 1987 in an effort to provide medical, social and nutritional support to mothers and children with HIV. At that time it was called the Family Centre and was taken over by the University Hospital of the West Indies in 1993. CHARES provides drugs to persons with HIV/AIDS. Clients pay minimal or no cost for antibiotics and other drugs for opportunistic infections but there is no provision for antiretroviral drugs.

Another Jamaican NGO, Food for the Poor International (a Catholic organiza-

tion) which has a clinic in downtown Kingston, is the only organization that makes available essential HIV medications to persons with HIV/AIDS at a cost that is less than the market value. It caters to the inner city communities and the very poor. Through the Food for the Poor International network many drugs are donated or imported at very low prices from Miami. This clinic has collaborated with a private medical practice in Miami where viral load and CD4 monitoring was done. The blood was drawn from clients in Jamaica and sent to Miami, and results were returned in 2-3 weeks. The clinic is currently developing a relationship with the central laboratories to facilitate these tests. The clinic is doing studies of the effects of different dosage levels on the amount of virus within the body. Apart from this example, other Jamaican NGOs are unable to provide needed antiretroviral drugs because of the overwhelming cost and the lifetime commitment to each client.

- In **Mexico**, a number of NGOs manage drugs banks, for which they obtain drugs through donations and low-cost purchases. This kind of initiative provides basic drugs such as antibiotics, pain relievers, nutritional supplements and some of the less expensive drugs for opportunistic diseases. Very occasionally antiretroviral drugs such as AZT, ddC and ddI may be available. In general, the NGO drug banks sell the drugs at a much cheaper price than on the commercial market. In some exceptional cases they are given for free. Supplies come from various sources, including donations from pharmaceutical laboratories and from several organizations in the USA.

Also in Mexico, groups of persons with HIV/AIDS have joined to try and increase their access to the drugs they need. These actions of people seeking a joint solution to a common problem have not always involved NGOs. As their activities become more



formalized, however, NGOs may become involved or the groups may set themselves up as NGOs in order to facilitate and expand their work. Mexico has a number of buyers' clubs of both types. The clubs are generally hosted by an NGO but some are managed directly by individuals without NGO involvement. The Mexican buyers' clubs sell basic drugs and also drugs for opportunistic diseases, but they specialize in providing drugs that are difficult to obtain. These clubs generally have the most recent medicines, sometimes even before the drugs are approved by the Mexican government. This was the case with the protease inhibitors and 3TC or d4T which were available from the buyers' clubs long before they appeared in pharmacies. The drugs come from the USA and are sold at low prices, though it is not clear whether their sources are pharmacies or donations. Expensive drugs for opportunistic infections, such as pentamidine and ganciclovir, are also available. Clients of these buyers' clubs tend to be wealthy.



- Drug banks are also operated by several NGOs in **Peru**. These operations are often at least partially paid for by the users and are supported by drug donations from within Peru and from abroad (though the latter are becoming less and less frequent due to high import taxes and to recent taxes on donations). The drug banks can provide antiretroviral therapy to very few people, and only for a short time, after which these persons must look elsewhere. Since the NGO budgets are very limited, most are not able to purchase medicines and distribute them. Some organizations do in fact obtain products at reduced prices from some pharmaceutical laboratories, though the NGOs are obliged to sell these to clients and in the end only persons with the money to purchase them can really benefit.

- **Venezuela** has a number of organizations that supply drugs to persons with

HIV/AIDS. Acción Ciudadana Contra el SIDA (ACCSI), for instance, set up a Drug/Medicine and Medical Equipment Bank in 1994. This distributes drugs free of charge to those in need and solicits financial contributions that are spent in purchasing drugs from a foundation, Fundación Artistas por la Vida, that negotiates special low prices with suppliers. The bank also provides 12 hospitals regularly with medical and surgical equipment. The drug and medical equipment bank is now run jointly by three NGOs with the help of donors (individuals, drug stores, NGOs, and hospitals) in the USA, international airlines, the Ministries of Health and Economics, the Venezuelan office of the Pan American Health Organization, the National AIDS Programme, custom offices and agents, warehouse owners, the police, truck drivers, and many volunteers. The drug bank is able to supply complete triple therapy (two anti-retrovirals plus Crixivan, Norvir or Invirase) to 12 persons, and one or two anti-virals to 28 persons (who pay for part of the therapy). Paediatric drugs are supplied to the children's hospital "J.M. de los Ríos".

Acción Solidaria is a Venezuelan NGO that was set up in Caracas in 1995 with the specific purpose of improving access to medications by procuring them at discounted prices or providing them outright. The organization has a "medicine bridge" by which drugs that are not available in Venezuela, or are too expensive there, are purchased in the USA and brought to Venezuela by volunteers. The prices are sometimes half what the drugs would cost if bought in Venezuela. Acción Solidaria also has a credit card fundraising campaign that enables the NGO to provide free-of-charge treatment to five women and five babies. A further fundraising campaign is expected to increase the number who can be helped in this way. In addition, the organization's "Compassionate Supply" programme provides antivirals for 10 women and 10 children.

The Fundación Artistas por la Vida was founded by a group of Venezuelan artists in 1992. The foundation has a pharmacy that offer ddI, zidovudine (generic AZT), d4T, ddC, 3TC, Indinavir, Saquinavir and Ritonavir. These drugs are purchased directly from the pharmaceutical industry by the foundation and sold to users at cost price. The foundation, which raises funds by hosting cultural events, has negotiated special prices with suppliers. Its monthly sale comprises about 500 triple therapy regimes and about 1,200 bi-therapy regimes.

The self-support group Asociación Luchemos por la Vida (ALVI) was founded in Venezuela in 1995. This group purchases medicines for users from the Fundación Artistas por la Vida. It also receives free supplies of drugs from ACCSI and Acción EcuMénica. ALVI also raises funds from individual donors and institutions in order to purchase medicines that are not available from these sources. Through donations from the local hospital "Enrique Tejera" and Ministry of Health funds, 12 children living with HIV/AIDS (average age 14 years) are supplied with necessary medicines.

Also in Venezuela, the "J.M. de los Ríos" children's hospital, which is part of the Ministry of Health system, also operates as a foundation. This enables the hospital to receive donations from private sources. Drugs for compassionate use are donated by pharmaceutical companies and by NGOs.

Information about drugs and treatment

● Sharing information is an important activity that is common to many NGOs. The types of information provided vary widely. For instance, in the

Brazilian State of Ceará, as in São Paulo, Rio de Janeiro, Rio Grande do Sul and other states, NGOs offer information to persons with HIV/AIDS about their rights to treatment under the law. This is part of a legal counselling service similar to that offered elsewhere. Two treatment bulletins are also produced locally, one of them since 1992. In Guatemala, on the other hand, an NGO gives education in HIV/AIDS prevention in public schools in seven departments of the country.

● A number of the NGOs in **Haiti** are involved in information work. Le Centre de Promotion des Femmes Ouvrières (CPFO), an NGO dedicated to improving the status of Haitian working women, provides health education and preventive services such as contraceptive advice and screening for sexually transmitted diseases. CPFO also conducts group discussion sessions for adolescents and partners of female factory workers at which information about HIV/AIDS is transmitted. Inter Aides PRODEVA, which is an AIDS prevention project for commercial sex workers and their clients, also gives information about contraceptive use and has a condom distribution network. Inter Aides PRODEVA has recently developed a credit programme for commercial sex workers.

Promoteur Objectif Zerosida (POZ Haiti), which was founded in 1995, implements a preventive education programme for adolescents in four regions. POZ Haiti has an information and advice hotline for youth, homosexuals and bisexuals, and people living with HIV/AIDS.

● Information sharing was one of the first tasks of AIDS NGOs in **Mexico**. In the 1980s some of Mexico's gay emancipation groups, such as Colectivo Sol in Mexico City, FGHT in Tijuana and Grupo Homosexual de Liberacion



(GHOL) in Guadalajara, were concerned mainly with dissemination of information among gays, because in the early days of the epidemic this group was the most affected. As the epidemic grew and affected other groups, other NGOs emerged and continued this work. Currently Red Mexicana de

personas que Viven con VIH/SIDA disseminates information about treatment and health care. Also in Mexico, NGOs distribute large amounts of information material on prevention on the widely celebrated Day of the Dead (2 November).

(2)-Since importation of drugs is strictly regulated in most of the countries of the Americas, drugs purchased abroad or obtained through donations made abroad should be declared as imported goods.

Resources

Many HIV-related drugs are beyond the economic reach of people.

The high cost of purchasing HIV-related drugs in countries of Latin America and the Caribbean affect both governments trying to provide health care with limited budgets and individuals attempting to get themselves appropriate treatment that is beyond their economic reach. Throughout the region there are groups of people living with HIV/AIDS joining together to share costs of treatment or to find ways of doing so. The efforts of these small groups are often not recorded but they represent a very meaningful form of solidarity funding.

- NGOs are doing fundraising both in their own countries and abroad to finance their activities (and particularly their provision of drugs). **Venezuela** presents an example of active fundraising and NGO cooperation, especially through the activities of the Fundación Artistas por la Vida organization. NGOs elsewhere are equally active within their own contexts. Jamaica AIDS support, for instance, generates income by painting clay pots and making aromatic candles. A group of volunteers known as "Friends of Jamaica AIDS Support" help keep the organization operative through their donations of money and time.

- Shortage of money for expensive drugs prompted the government of **Colombia** to set up its National Medicine

Fund for High Social Impact Diseases. The fund aims to make medicines for AIDS, cancer and haemophilia accessible to persons with limited financial resources by subsidizing drug purchase through NGOs and other bodies.

- The high cost of HIV-related drugs in **Chile** affects both persons who have private health insurance and those who depend on the public health system. The for-profit health providers, whose users tend to come from higher-income groups, do not normally cover the cost of drugs and most of their insurance plans place an upper limit on total costs. The public health system provides basic prophylactic drugs, along with standard control examinations such as CD4 counts (although not viral load as yet). Aciclovir and fluconazole are sometimes available. AZT was added to the treatment protocol in 1993.

The current budget request for drug purchases is US\$2.1 million. The AZT+3TC double therapy, offered as standard treatment, costs the government just under US\$400 monthly per patient. With some 3750 HIV-positive persons as of 30 June 1997, double therapy for all would cost much more than the amount requested, even excluding patients not covered by the public health system. These figures, of course, do not include the use of protease inhibitors.

Drug shortages in Chilean hospitals have been handled in a variety of ways. Some hospitals even opted for lotteries in which all eligible patients' medical folders were placed in a container, a certain number of winning folders were drawn out and those persons were then entitled to receive treatment. Other hospitals sought to discourage patients who were already too ill or who were not ill at all. One hospital encouraged patients to form an NGO to contact businesses to seek drug "adoption" agreements by which a company would pay for their treatment.

● In **Mexico** the Minister of Health presented a proposal in 1996 to create a fund (Fideicomiso) for ensuring treatment for people with HIV/AIDS. The proposal, which was drawn up by the Faculty of Medicine of the Autonomous National University of Mexico, set up a fund to buy drugs for people with HIV/AIDS who have no access to the social security health services. The intention is that the 60 million dollar fund will be financed by the private sector—particularly hotels, night clubs, and wine and liquor manufacturers.

Cooperation and coordination

The necessity of cooperation and collaboration amongst NGOs.

As more and more NGOs have become involved in work related to AIDS, cooperation and collaboration have become not only desirable but also necessary in order to maximize impact and eliminate unnecessary overlap. As in other areas of activity the situation varies from country to country.

● In **Argentina**, more than 50 NGOs that report doing HIV/AIDS work or conducting related programs have been officially registered. Three AIDS-related national networks are currently operating in the country: Red de ONG de la Argentina, Coalición de ONG con Trabajo en SIDA de la República Argentina, and Encuentro de ONG. Only the latter two appear to have been active during the past year. NGOs are also integrated into local networks that concentrate on different interventions aimed at improving access. These have been of vital importance as information providers.

● By July 1997, **Brazil** had 520 organizations doing work of some kind in rela-

tion to AIDS. Annual meetings are held of Brazilian AIDS NGOs, and the 1997 meeting was received by the President. These meetings elect representatives to the National Committee of anti-HIV Vaccines, to the National AIDS Commission and, since 1996, to the National Health Council. In addition, since 1991 national meetings of people affected by HIV/AIDS have taken place each year in Rio de Janeiro. A national network of people with HIV/AIDS was founded in 1995 and has held five regional meetings since then, attended by more than 500 people living with HIV/AIDS.

● In **Chile**, Red de Acción Comunitaria en VIH-SIDA (ACAN) was formed in 1991 to link NGOs, both those doing AIDS-related projects and those that are AIDS-exclusive organizations. ACAN now has a floating membership of some 15 groups. There is also a grassroots coalition - the El Bosque AIDS Network - that deals with HIV in poor areas. For people living with HIV/AIDS, Coordinadora Nacional de Personas

Viviendo con el VIH (COORNAVIH) brings together a variety of groups and is the focus of a number of activities.

- Also for people living with HIV/AIDS, in **Costa Rica**, Fundacion Vida has joined the gay support group Triangulo Rosa to lead a patients' coalition that is campaigning for access to treatment. In Guatemala a multidisciplinary network of agencies working with HIV/AIDS and related issues, called the Coordinadora de Lucha contra el SIDA (CSLS), consists of more than 40 national NGOs, government agencies (including the police and army), religious groups, and international NGOs and funding agencies. Regional cooperation between NGOs, and especially between organizations of people living with HIV/AIDS, is increasing in Central America. There has been a growing exchange between Costa Rica, Guatemala, Nicaragua and Panama. The English-speaking Caribbean countries are trying to develop cooperation in order to get access to treatment.

- The government of Haiti formed the National AIDS Commission (CNLS) there in 1987. This is an interministerial and intersectoral body comprised of members from the public and private sectors. The coordinating office for the National AIDS Programme (BCNPLS) was established in 1988 but this structure no longer exists.

At the time of writing this report, only one person was coordinating the National AIDS Programme assisted by an ad hoc commission.

- AIDS-related NGOs in **Jamaica** range from small community based organizations that also work with the poor in general to advisory bodies made up of many NGOs, community organizations, and some private voluntary organizations and church groups. The National AIDS

Committee (NAC) was established in 1988 as a registered private voluntary organization and a member of the council of voluntary social services. The NAC, which is advisory to the Minister of Health and coordinates AIDS control activities, comprises 75 private and public sector organizations that make up five committees chaired by professional persons such as a lawyer, physician, epidemiologist, psychologist and educator. The NAC encourages networking between NGOs. Lack of sufficient resources is a hindrance to achieving collaborative goals but the willingness to participate in a joint humanitarian effort makes the collaboration important. At this level all NGOs share information, which makes it easier for NGOs to be aware of what others are doing.

- In **Mexico**, the first national meeting of people living with HIV/AIDS took place in 1995, bringing together more than 100 persons. This resulted in the formations of the Frente Nacional de Personas que Viven con el VIH/SIDA (FRENPAVIH). This has a liaison function between people living with HIV/AIDS, NGOs concerned with HIV/AIDS and the government.

- The need for cooperation between AIDS NGOs in **Peru** has led nine of them to form a network called Asociación Red SIDA Perú in order to promote collaboration, conserve resources and strengthen the national response to HIV infection. The network includes PROSA, an organization representing people living with HIV/AIDS.

- Similarly, NGOs in **Puerto Rico** have formed their own alliance of AIDS NGOs that meets on a regular basis to plan strategies for furthering access to treatment and drugs. NGOs have established a cross-referral system as a way of making sure that clients have access to as many NGO resources as possible.

The cross-referral system means that if an NGO cannot provide a client with a particular service for any reason, staff will refer the client to an NGO or government institution that is able to do so.

- In **Venezuela**, the Red Nacional en Derechos Humanos y SIDA was founded in 1994. This has expanded in the past few

years and now comprises 13 national AIDS service organizations and human rights organizations that include AIDS in their programmes. In January 1995, the Red Metropolitana de Organizaciones con Servicio en SIDA/Red MetSIDA was established, with the main objective of reinforcing individual NGO activities and to offering support services to its members.

Conclusions

The advantages and limitations of NGO activities to improve access to HIV-related treatment.

Types of NGO activity

This review has shown that NGOs in Latin America and the Caribbean are involved in a variety of activities to improve access to HIV-related treatment for people living with HIV/AIDS. Some of these activities have succeeded in providing access to treatment, whether antiretrovirals or treatment of opportunistic infections, for a limited number of people who would otherwise have received no treatment. Other activities have drawn attention to the lack of equity in access or to discrimination against people living with HIV/AIDS. These activities have been very important from an ethical point of view since they highlight the difficult situation of people living with HIV/AIDS. NGO activities also show that a compassionate response, albeit a limited one, is possible even in resource constrained settings.

Advocacy as a long-term strategy

The effectiveness of the various types of NGO activities—advocacy, legal action and actual drug supply—varies in terms of outputs and outcomes. Advocacy does not yield an immediate output with a quick change in a country's situation but it may have a significant impact in the long term. Several NGOs described in this review have been successful in influencing the laws of their countries to improve the pre-

vention and care situation for people living with HIV/AIDS. In Costa Rica and the Dominican Republic, NGOs have contributed to the development and monitoring of laws aimed at preventing discrimination against people living with HIV/AIDS. In Mexico and Brazil, public demonstrations resulted in increased access to certain drugs under the social security scheme for a clinically selected group of people living with HIV/AIDS. These are just a few of the examples from across the region. It is difficult to measure the direct results of advocacy, but it is clear that advocacy contributes to a change in social and political attitudes. Ultimately such a change in attitudes leads on in a number of cases to a change in the law or in the allocation of resources.

Advocacy is undoubtedly a very appropriate activity for an NGO to undertake. Advocacy and activism require no physical structures or expensive equipment but rather human courage and commitment and the ability to organize around a cause or a goal. Advocacy is sustainable in situations of very limited resources. NGOs are often particularly good at reacting to opportunities based on economic and social changes in their societies. NGO activists may be more flexible than government officials who function within a fixed institutional framework. This NGO flexibility may contri-

bute to the long-term sustainability of advocacy efforts. The data reviewed for this report indicate that advocacy may contribute to creating a favourable environment for an increased supply of HIV-related drugs.

The wider implications of taking legal action

In some countries there are laws or constitutional rights that guarantee access to health care for all citizens. However, as is often the case in developing countries, there may not be the institutional or management capacity to implement or enforce these laws. Taking legal action against public or private institutions may, in some cases, serve to improve access to HIV-related drugs for some people living with HIV/AIDS. But in other cases, even in the presence of laws guaranteeing treatment of HIV-infected people, legal action is of little help if the public or private supply of drugs to health facilities continues to be insufficient and irregular. However, legal actions are often highly visible and they are in themselves messages of advocacy that highlight social injustice or inequity. As such, they may have a long-term effect which goes beyond the individual legal case to change social attitudes in the society.

NGOs cannot replace governments in terms of ensuring access to HIV-related drugs

Many NGOs, from private hospitals to advocacy groups, provide drug supplies. These supplies are often based on the availability of funds or donations of drugs. This means that supplies are often irregular and they can at most be supplementary to other public and private sources of drugs. Irregular supplies of certain drugs can be dangerous for temporary shortages of drugs may cause patients to relapse or

lead to the development of resistant strains of the HIV virus. NGO drug supply coverage is also limited to special groups or selected geographical areas, often cities. Supply activities by NGOs cannot replace the need for governments to ensure access to health care and drugs for all their citizens. Only governments can ensure equitable access and coverage of health care in rural and urban areas, and for all social groups. On the other hand, NGOs supplying drugs do enable more people to get access to the drugs that they need and provide hope for people in situations of despair. In addition, they highlight the inadequacies of the public and private health systems, which may contribute towards pressure for improvements.

Table 4 shows countries' Gross Domestic Product (GDP) per capita per AIDS prevalence. This table illustrates that countries with relatively fewer numbers of AIDS cases and relatively higher GDP have potentially more resources to respond to the epidemic through care or prevention. However, the actual resources allocated to HIV/AIDS prevention and care may not always reflect the resource situation in the country. Some countries with relative fewer resources have better access to HIV-related drugs than their level of resources would indicate. The issue of resource allocation to HIV-related drugs must therefore be seen in a broader political and social context depending on the country in question.

Information sharing contributes to effective utilisation of limited resources

Information about HIV infection and its treatment is provided by a number of NGOs in Latin America and the Caribbean. This type of activity is very important for people living with HIV/AIDS. People need to know how to evaluate their symptoms and where to go

for help. Such information enables a better utilization of existing resources and contributes to empowerment of people living with HIV/AIDS. It also provides a focus for collaboration and exchange between NGOs. Such collaboration can lead to a referral system, as seen in Puerto Rico, by which if an NGO cannot provide a client with a particular service or drug, the client will be referred to another NGO or a government institution that is able to do so.

NGOs: advantages, constraints and ways forward

There are many actors in the field of providing care for people living with HIV/AIDS. Governments have the ultimate responsibility of ensuring access to care, whether through private channels or in public facilities. Other stakeholders such as private insurance companies, labour unions, industries, the media and people living with HIV/AIDS also have important roles to play. NGOs work in this complex context and their types of activity depend on the specific social, economic and legislative environment. One of the comparative advantages of NGOs is that they can respond quickly to changing care needs and possibilities (new drugs, new diagnostic equipment, etc.) caused by the HIV epidemic. NGOs are flexible, a quality that enables them to respond immediately to needs and opportunities that may arise as a result of changing political environments. They are also in a good position to raise sensitive issues and ask questions that nobody else feels able to ask. Their members stress controversial issues without institutional or political constraints. And the commitment of people working in NGOs is such that much work is carried out with very limited financial resources.

However, some of the same characteristics that make NGOs effective also

make them vulnerable. The flexibility that allows them to pursue opportunities may also, in some cases, encourage a more donor-driven approach whereby programmes and activities may change substantially from one funding cycle to the next. This can lead to programmes being more dependent on the priorities of donors than on locally defined needs⁽³⁾. Sometimes this situation leads to competition between NGOs that seek funding from the same sources, rather than to collaboration. This vulnerability is linked to the problem of sustainability for most NGOs, an issue that should be addressed both by NGOs and by donors. A reasonable proportion of funds should be earmarked, as a matter of policy of both NGO and donor, to promote the internal sustainability of NGOs through locally appropriate mechanisms such as obtaining public utility status, capacity-building, and so on.

More collaboration between NGOs, both within countries and between countries, is necessary to strengthen their work and achievements. Such collaboration could be promoted through the creation of NGO networks. Where such collaboration has already begun in the form of associations or referral systems, efforts should aim to try to support and expand them. In addition, collaboration with other stakeholders, such as United Nations Theme Groups on HIV/AIDS, private health insurance companies and pharmaceutical companies, would also stimulate a more effective utilization of human and financial resources. The Joint United Nations Programme on HIV/AIDS hopes to be able to stimulate and facilitate such partnerships to improve access to care for people living with HIV/AIDS in Latin America and the Caribbean.

(3)- *The same arguments may apply to institutional actors.*

Annex 1

Table 1: 1995 annual AIDS incidence rate per 1000,000 inhabitants

Anguila**	142.2	Jamaica	206.4
Antigua & Barbuda	90.9	Martinique	100.3
Argentina	48.2		
Aruba	N/A	Mexico	46
Bahamas	1413	Montserrat**	95.7
Barbados	362	Nederland Antilles	381.9
Belize	129.6	Nicaragua	4.7
Bolivia	1.9	Panamá	77.2
Brazil	***95.2	Paraguay	4.6
Cayman I.**	111	Perú	43.9
Chile	19.6	Puerto Rico*	656.2
Colombia	25.6	R. Dominicana	56.4
Costa Rica	59.9	Saint Kitts & Nevis	112.6
Dominica	60.2	St Vincent & Grenadines	50.1
Ecuador	6	Santa Lucia	63.3
El Salvador	65.9	Surinam	47.3
French Guiana	847.5	Trinidad & Tobago	260.1
Granada	190.9	Turks & Caicos**	1397.2
Guadalupe	243	Uruguay	39.9
Guatemala	13.3	Venezuela	36.4
Guyana	115.1	Virgin I. (UK)	230.1
Haiti**	119.3		
Honduras	168.9	Latin America	58.5

* 1995 data included in US

** zero or N/A in 1995; the figure corresponds to the last available data

*** In data provided by the Brazilian National STD/AIDS Programme this figure is 109/1000,000.

Source: Calculated by Jorge Beloqui on the basis of data from PAHO: Vigilancia del SIDA en las Américas, Informe Trimestral. 10 de junio de 1997. Programa Regional de SIDA/ETS. División de Prevención y Control de Enfermedades. OPS/OMS OPS/HCA/97006. Cuadro 1, Cuadro 2.

Table 2: AIDS cases 1995

	AIDS AC. CASES 1995 (PAHO 1997)	1995 POPULATION IN 100,000 (PAHO 1996)	AIDS RATE 1995
Anguila	5	0.08	63
Antigua & Barbuda	68	0.66	103
Argentina	10543	342.67	31
Aruba	21	0.7	30
Bahamas	2101	2.76	761
Barbados	632	2.61	242
Belize	160	2.17	74
Bolivia	120	74.04	2
Brazil*	92225	1614.69	57
Cayman I.**	18	0.31	58
Chile	1542	142.42	11
Colombia	6674	351.01	19
Costa Rica	954	34.24	28
Dominica	37	0.71	52
Ecuador	543	114.76	5
El Salvador	1372	57.68	24
French Guiana	544	1.4	370
Granada	81	0.92	88
Guadalupe	677	4.28	158
Guatemala	804	106.21	8
Guyana	698	8.34	84
Haiti**	4967	71.8	69
Honduras	5278	56.63	93
Jamaica	1533	25.47	60
Martinique	367	3.79	97
Mexico	25746	903.2	29
Montserrat**	7	0.11	64
Nederland Antilles	233	1.99	117
Nicaragua	127	41.4	3
Panama	1043	26.31	40
Paraguay	193	48.94	4
Perú	4884	238.55	20
Puerto Rico***	13980	36.74	381
Dominican Rep.	3380	79.21	43
Saint Kitts & Nevis	48	0.41	117
St Vincent and G	68	1.12	61
Santa Lucia	76	1.42	54
Surinam	209	4.09	51
Trinidad & Tobago	2083	13.06	159
Turques & Caicos I.**	39	0.14	279
Uruguay	684	31.85	21
Venezuela	6206	214.91	29
Virgin I. (UK)	11	0.19	58
Latin America	734214	4609.14	16

*Data provided by the Brazilian National STD/AIDS Programme indicate that this figure should be 96,681

**Last data prior to December 1995.

***Included in US total.

Source: Calculated by Jorge Belouqui on the basis of data from PAHO: Vigilancia del SIDA en las Américas, Informe trimestral. 10 de junio de 1997. Programa Regional de SIDA/ETS. División de Prevención y Control de Enfermedades. OPS/OMS OPS/HCA/97006. Cuadro 1, Cuadro 2

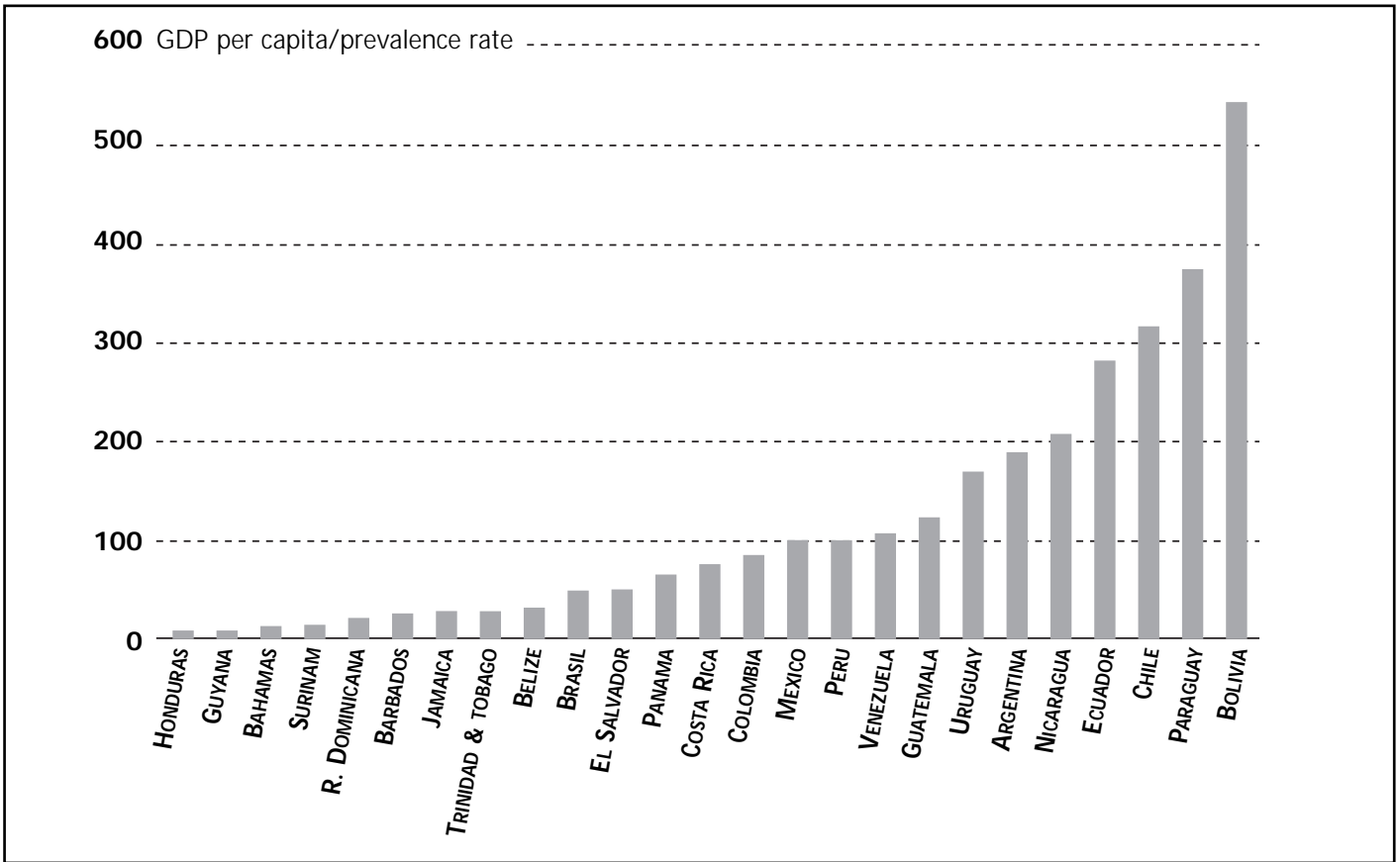
Table 3: HIV-related drugs in Latin America and the Caribbean

EXPLICIT HIV/AIDS DRUG POLICY. LAW, DECREE, RESOLUTION				TYPE OF TREATMENT				
COUNTRY	PUBLIC HEALTH SYSTEM	SOCIAL SECURITY	PRIVATE INSURERS	ANTIRETROVIRALS		OPPORTUNISTIC INFECTIONS	SYMPTOMATIC	PREVENTION OF MTCT*
				NUCLEOSIDE ANALOGUE	PROTEASE INHIBITORS			
Argentina	Yes (law 23789)	Yes (law 24455)	Yes (law 24754)	Yes	Yes	Yes	Yes	Yes
Brazil	Yes (law 9313)	Resolution 1401 (CFM)	Yes	Yes	Yes	Yes	Yes	Yes
Chile	Yes		No	Yes some	No			
Costa Rica	Supreme court ruling	Yes			Yes	Yes		
Colombia	Yes (Law 100, decree 1543)	Yes	Yes	Yes	No			
Cuba	Yes (partially depending on donations)	Yes		Yes	Yes	Yes	Yes	Yes
Grenada	No	No	No	No				
Guatemala	Yes (pregnant)	No	No	No	Interferon	TB		Yes
Haiti	No	No	No	No	No			
Honduras	No	No	No	No				
Jamaica	No	No	No		No	TB		
Mexico	Yes. Implant	Yes INSS			Yes			
Paraguay	Yes	No	No	Yes				
Perú	Yes (pregnant) (law 26626)	Yes AZT + some IO	Implant	Yes				
Dominica R.	No	No	No	No	No	No	TB	
Uruguay	Yes. Min. Health Resolution	Yes (10%). Law Project		Yes	Yes	Yes	Yes	Yes
Venezuela	No	There are approved court appeals	No	Yes	Yes	Yes	Yes	Yes

*Mother to child transmission.

Source: Weissenbacher & Beloqui 1997 (personal communication).

Table 4: GDP per capita/AIDS prevalence



Source: Jorge Beloqui. *AIDS/NGOs and access to AIDS drugs in Latin America and the Caribbean*, Appendix 3, November 1997.

Annex 2

List of NGOs

Argentina

Coalición de ONGs con Trabajo en SIDA de la Republica Argentina
Encuentro de ONGs
Red de ONGs de la Argentina
SPES

Brazil

Since there are more that 500 NGOs with activities related to HIV/AIDS in Brazil, we refer to:

- Catálogo de Organizações Não Governamentais. CNDST/AIDS (1996)
M. Da Saúde.
Esplanada dos Ministérios, Bl G, Sobreloja, Sala 110
(70058-900) Brasília DF
Fax 5561-315-2519/2643
E-mail: <aids@aids.gov.br>
- Catálogo de Entidades Civis com Atividades em HIV/AIDS. ABIA (1997)
Av. Rio Branco 43, 22 andar.
(20090-000) Rio de Janeiro RJ
Fax: 5521-253-8495; 224-1654
E-mail: <abia@ax.apc.org>

Chile

AIDS and Community Action Network (ACAN)
Centro de Apoyo a las Personas con VIH (CAPVIH)
Corporación Chilena de Prevención del SIDA (CChPS)
Coordinadora Nacional de Personas Viviendo con VIH (COORNAVIH)
El Bosque AIDS Network
Laura Rodriguez Foundation
Popular Health Education Project (Lutheran Church)
Red de Acción Comunitaria en VIH-SIDA

Colombia

Acción Por Vida
EUDES Foundation
FIASAR
FUNDAMOR
Liga Colombiana de Lucha contra el SIDA (LCLCS)
Ser Humano

Costa Rica

Centro Por La Justicia y El Derecho Internacional (CEJIL)
Fundación Vida
Triangulo Rosa

Dominican Republic

CEBOPRETSIDA
COCOES
CONSAVIVE
Coordinadora de Vigilancia contra el SIDA (COVICOSIDA)
COPRECOETS
Fundación Félix Vásquez
FUNDAVI
Hermanas Adoratrices del Santisimo Hogar de Mary Loly
Instituto Dominicano de Seguros Sociales (IDSS)
PASOVI
Patronato de Lucha contra el SIDA (PLUS)
Patronato de Solidaridad (PASO)
Unidad de Atención Integral a Personas Viviendo con el VIH/SIDA

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Guatemala

ACENCAI
ARCEGAL
Asociación Guatemalteca para la
Prevención y Control del SIDA (AGPCS)
Asociación para la Prevención y Ayuda a
Pacientes con SIDA (APAES)
Asociación Regional Centroamericano de
Gays y Lesbianas (ARCEGAL)
Coordinadora de Lucha contra el SIDA
(CSLS)
Hospicio Casa San José
Maryknoll Order (Roman Catholic
Church)
Instituto Católico de Capacitación
Arquidiócesis de Quetzaltenango
Proyecto VIDA
Organización de Apoyo a una Sexualidad
Integral frente al SIDA (OASIS)

Haiti

Centre de Promotion des Femmes
Ouvrières (CPFO)
Groupe Haitien d'Etudes de Sarcome de
Kaposi et des Infections Opportunistes
(GHESKIO)
Haitian Centre for Social Services
(CHASS)
Hôpital de Fermathe (Baptist Church)
Hôpital des Petits Frères et Soeurs
(Roman Catholic Church)
Hôpital St Croix de Léogane (Roman
Catholic Church)
Promoteur Objectif Zerosida (POZ Haiti)
Inter Aides PRODEVA

Jamaica

Caribbean Forum of Lesbians, All-sexuals
and Gays (C-FLAG)
Caribbean Network for People Living
with HIV/AIDS (CRN+)
Centre for HIV/AIDS Research,
Education and Services (CHARES)
Food for the Poor International (Roman
Catholic Church)
Friends of Jamaica AIDS Support
Hanover AIDS Support
Jamaica AIDS Support

Mexico

ACASIDA
Acción Humana por la Comunidad
Amigos contra el SIDA
Asociación Mexicana de Servicios
Asistenciales en VIH/SIDA
AVE de Mexico
Centro de Atención Profesional a
Personas con SIDA (CAPPSIDA)
Centro de Investigación y Terapéutica
Avanzada en Inmunodeficiencias (CITAID)
Colectivo Sol
CONSIDA
FGHT (Tijuana)
Frente Nacional de Personas Afectadas
por el VIH/SIDA (FRENPAVIH)
Fundación Mexicana de Lucha contra el
SIDA
Grupo Homosexual de Liberación
(GHOL)
Mexicanos contra el SIDA
Network of People Living with HIV/AIDS
Red Mexicana de Personas que Viven con
VIH/SIDA
Red Nacional en Derechos Humanos y
SIDA
Ser Humano

Peru

Asociación Red SIDA Peru
Grupos de Ayuda Mutua
PROSA

Puerto Rico

(no NGOs named)

Venezuela

Acción Ciudadana Contra el SIDA
(ACCSI)
Asociación Luchemos por la Vida (ALVI)
Acción Solidaria
Fundación Artistas por la Vida
Red Metropolitana de Organizaciones
con Servicio en SIDA (Red MetSIDA)
Red Nacional en Derechos Humanos y
SIDA