

HIV - AIDS

HIV - AIDS and Human Rights

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**The International Guidelines on
HIV/AIDS and Human Rights**

An assessment of national responses in improving

access to HIV/AIDS treatment within the framework

How are they being used and applied?

of the International Guidelines on HIV/AIDS and

Human Rights, and the role played by the

Community Sector.

A C K N O W L E D G E M E N T S

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ICASO works to strengthen the community-based response to HIV/AIDS in all the regions of the world. Our mission is to:

- mobilize communities and their organizations to participate in the response to HIV/AIDS;
- articulate and advocate the needs and concerns of communities and their organizations;
- ensure that community-based organizations, particularly those with fewer resources and within affected communities, are strengthened in their work to prevent HIV infection, and to provide treatment, care and support for people living with and affected by HIV/AIDS;
- promote the greater involvement of people living with, and affected by HIV/AIDS in all aspects of prevention, treatment, care and support, and research;
- promote human rights in the development and implementation of policies and programs responding to all aspects of HIV/AIDS.

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TABLE OF CONTENTS

Acknowledgements.....	i
Glossary.....	iii
REPORT SUMMARY	v
INTRODUCTION	1
The International Guidelines on HIV/AIDS and Human Rights.....	1
The Research Project.....	2
Project Goals	2
Project Objectives.....	2
Method.....	2
How the Results Are Organized.....	4
OBSERVATIONS FROM THE RESEARCH.....	5
Access to Treatment.....	5
The Human Rights Approach to HIV/AIDS.....	6
Right to Health	7
Access to Treatment as a Human Right?	8
Drug Pricing.....	10
Two Case Studies.....	12
South Africa: An Example of Community Involvement.....	12
Latin America: An Example of the use of courts to gain access to treatment	15
Situation by Country.....	17
Right to Health & Essential Drugs List	
Access to Treatment	
Government and Pharmaceuticals	
Community Participation	
International Guidelines	
CONCLUSIONS.....	35
RECOMMENDATIONS FOR FURTHER ACTION.....	37
APPENDIX:	
List of Countries Selected for the Research	37
List of Countries with NGO Participation in the Research.....	37
Participating NGOs	38

G L O S S A R Y

AIDS:	Acquired Immune Deficiency Syndrome
HIV:	Human Immunodeficiency Virus (Note: for this questionnaire it is understood that HIV causes AIDS)
ASO:	AIDS Service Organization
NGO:	Non Governmental Organization
CBO:	Community Based Organization
PLHAs/PHAs/PLWAs/PWAs:	People living with HIV/AIDS
STD:	Sexually transmitted disease
Adult:	person in the age of 15-49
Children:	person in the age of 0-14
Treatment for HIV/AIDS (HIV/AIDS Treatment):	for the purpose of this questionnaire, treatment for HIV/AIDS only includes Antiretroviral drugs and treatment for opportunistic infections (see below).
Antiretroviral drugs (ARVs):	By antiretroviral drugs we mean a class of therapies including drugs such as: AZT (Retrovir), 3TC (EpiVir), ddI (Videx), ddC (Hivid), d4T (Zerit), 1592 (Abacavir), AZT & 3TC (Combivir - which is counted as two antiretrovirals).
Protease inhibitors:	Saquinavir (Invirase), Indinavir (Crixivan), Ritonavir (Norvir), Nelfinavir (Viracept), Saquinavir (Fortovase).
Non-nucleoside reverse transcriptase inhibitors:	Nevirapine (Viramune), Delavirdine (Rescriptor), Efavirenz (Sustiva), Loviride
Combination therapy:	any two or more drugs taken together
World Trade Organization (WTO):	The global international organization dealing with the rules of trade between nations.
TRIPS agreement:	(Trade-Related Aspects of Intellectual Property Rights.) The TRIPS Agreement establishes minimum standards in the field of intellectual property. All Member States have to comply with these standards by modifying their national regulations to be in accordance with the rules of the Agreement.
Essential Drugs List:	The Essential Drugs List forms a major component of the National Drug Policy, as it lays the foundation for ensuring the availability of essential medicines to all citizens. (Essential drugs are those that satisfy the needs of the majority of the population. They should therefore be available at all times, in adequate amounts, and in the appropriate dosage forms).
MSM:	men who have sex with men

IDU:	Intravenous Drug users
US\$:	United States dollar
Elisa and Western Blot tests:	The ELISA and western-blot are 2 different laboratory techniques used to detect the presence of antibodies. It is a preliminary screening tool used to detect either the presence of antigen or antibody in the blood. The ELISA test is commonly used for screening. The Western blot test checks positive ELISA tests.
CD4/T-cell test:	The CD4 / T-cell test measures the number of CD4 cells (T-cells) per millilitre of blood. These cells are a part of the immune system
Viral load:	this test measures the amount of HIV in the blood, in parts per millilitre.
Generics:	Generic medicines are pharmaceuticals promoted and marketed using chemical names rather than the brand names developed by manufacturers. These drugs are sold at considerably lower prices than brand name medicines, primarily because they are not saddled with advertising budgets essential to brand name promotion. The only difference therefore between a brand name drug and its generic counterpart is the name.
International Guidelines on HIV/AIDS and Human Rights (International Guidelines or IG). U.N.C.H.R. Res. 1997/33, U.N. Doc. E/CN.4/1997/150 (1997).	You can access it at: http://www.unaids.org/publications/documents/human/law/hrigh t2e.doc
ICASO:	International Council of AIDS Service Organizations
	The NGO Summary of the International Guidelines on HIV/AIDS and Human Rights and the Advocates Guide An Advocate's Guide to the International Guidelines on HIV/AIDS and Human Rights can be accessed at: www.icaso.org

Assessment of country responses in improving access to HIV/AIDS treatment within the framework of the International Guidelines on HIV/AIDS and Human Rights and the role played by the Community Sector.

R E P O R T S U M M A R Y

In 1996, the Second International Consultation on AIDS and Human Rights organized by UNAIDS and the UN Commission on Human Rights issued guidelines to member states to assist them in designing programs and policies which protect and promote human rights in the context of confronting the AIDS pandemic. ICASO undertook a community research project to try to get a clear indication on how that process has progressed by focusing on a particular aspect of the pandemic response: access to quality treatment and the role that communities have played in improving that access. Funding for the research project was generously provided by the Japanese Foundation for AIDS Prevention.

The research compiled information on how a selected number of countries have responded to the recommendations and how the community sector has participated in the implementation of one aspect of Guideline 6 - 'safe and effective medication at an affordable price'. The process would also assess the level of dissemination and popularisation of the International Guidelines on HIV/AIDS and Human Rights (IGHR) at national levels

From the onset of the AIDS pandemic, communities responded when there was no one else, often in the face of government denial. Community organizations have the knowledge and expertise to work effectively with those most at risk of HIV infection and vulnerable to AIDS. A strong community response, moreover, is a key indicator of a successful national response. Through this project, we wished to identify and document good practices by communities and governments

Forty non-governmental HIV/AIDS organizations were invited to participate, from a total of 21 countries. A total of 21 organizations responded from 15 countries.

Access to treatment issues that were identified:

- Drug prices: the cost of the therapy impedes access for more than 90% of the population living with HIV/AIDS.
- Other factors that can be related to the affordability of ARVs: patents, limited supply, import duties, taxes, and distribution

Seventeen NGOs that participated in the research had previously heard of the International Guidelines. They cited UNAIDS, UNDP, WHO, ICASO and AfriCASO as the primary sources of information on the guidelines. Of the seventeen, only six of the NGOs have actually incorporated the guidelines into their advocacy work. Of these NGOs, two were involved in the original drafting of the guidelines and have since disseminated or distributed them to other organizations. The majority of the respondents believed that the guidelines provided a useful tool for advocacy and filled a void in countries that lacked HIV/AIDS and human rights legislation. The creation of international standards and recommended plans were cited as particularly significant.

Only 6 of the 15 governments have formally incorporated the guidelines into national legislation. However, many governments have been influenced by the general principles of the guidelines or have referred to them in national AIDS policies. For instance, although Japan has not included them in national legislation, in 1999, the Minister of Health and Welfare added human rights issues to its research project on HIV/AIDS.

- Inadequacies in the health infrastructures of many developing countries
- Lack of accurate information to even define the extent of the epidemic within some countries.

Understanding and responding to access to treatment issues begins with the broader issue of the right to health. Right to health is a fundamental human right and in that context, access to treatment is a human rights issue.

The increasing influence of NGOs working on HIV/AIDS, which has brought about tangible changes in public policies, cannot be ignored. Many authors recognize the influence of civil society in the design and execution of public policies. The constant lobby actions performed by NGOs with different governmental officers, their critical educational and social assistance function, especially in relation to marginalized economic/social classes, their permanent participation in the media to inform about problems regarding human rights and HIV/AIDS, their street demonstrations as well as the promotion of legal ways to safeguard human rights of people living with HIV/AIDS, constitute clear examples of the NGOs' influence on public policies around the world. Two large scale examples, one of using the legal systems in South America and the public campaign of the Treatment Action Campaign (TAC) demonstrate the enormous effort that people with HIV and the community sector is undertaking to make access to medication a reality.

The main Conclusions of the report are:

- NGOs considered that the guidelines are a tool to advocate for improvements in the situation of HIV/AIDS. However, almost all indicated that they have not been broadly distributed to grass roots organizations.
- The guidelines in general are not widely used by advocates and have not been incorporated into national legislation.
- Anti-retrovirals are available but are not accessible to the general population. Price is a key factor.
- Even though the prices of medications are very high, pricing is not the only reason for the lack of ARVs in some countries. Weak health infrastructures play a big role in the unavailability of ARVs in some countries.

RECOMMENDATIONS FOR FURTHER ACTION

The guidelines are a useful tool for education and advocacy, however, they need to be more widely promoted both to governments and to the community sector. This promotion can be enhanced by the UN system to its member States and to non-governmental organizations by the UN system of agencies and by Community Sector networks.

The profile achieved by UN Declaration of Commitment on AIDS in 2001 is an opportunity for community advocates to promote the human rights based approach and practical strategies outlined in the guidelines.

More organizations in the Community Sector need to themselves integrate a human rights based approach to their work and their advocacy. Opportunities for related training and discussion of strategies need to be made available to ensure a strong community response.

I N T R O D U C T I O N

The International Guidelines on HIV/AIDS and Human Rights

The International Guidelines on HIV/AIDS and Human Rights (International Guidelines, IG or IGHR) were prepared for, and adopted by, the Second International Consultation on HIV/AIDS and Human Rights, held in Geneva, Switzerland in September of 1996. This consultation brought together 35 experts – government officials, People Living With AIDS (PLWAs), human rights activists, academics, representatives of regional and national networks on ethics, law and human rights, and representatives of United Nation’s bodies and agencies, NGOs and ASOs. The 12 guidelines attempt to take existing human rights norms and mould them into a series of practical, concrete measures which states can adopt to fight the epidemic.

In 1997, 1999 and 2001 the UN Commission on Human Rights adopted resolutions calling on governments and other actors (NGOs) to report on the steps taken to promote and implement the International Guidelines. In fact the resolutions requested the *Secretary-General to solicit comments from Governments, United Nations organs ... and International and non-governmental organizations on the steps they have taken to promote and implement the Guidelines ... and to submit, in consultation with interested parties, a progress report for consideration ...*

The aim of the guidelines is to translate international human rights standards into practical observance at national level. The guidelines follow 3 inter-linked approaches:

- widespread reform of laws and legal support services (with focus on women, children and vulnerable groups);
- improvement in the acknowledgement of Governments’ responsibility for multi-sectoral coordination and;
- support for increased private sector and community participation in the response to the epidemic.

ICASO undertook a community research project to try to get a clear indication on how that process of translation has progressed by focusing on a particular aspect of the pandemic response:

- access to quality treatment and the role that communities have played in improving that access.

The Research Project

From the onset of the AIDS pandemic, communities have responded as best they could, often in the face of government inaction or denial. Community organizations have the knowledge and expertise to work effectively with those most at risk of HIV infection and vulnerable to AIDS. A strong community response, moreover, is a key indicator of a successful national response. Through this project, we wished to identify and document good practices by communities and governments.

The research project assessed country responses in improving access to HIV/AIDS treatment within the framework of the International Guidelines on HIV/AIDS and Human Rights. Guideline 6 recommends that States enact laws and regulations to ensure the widespread availability of good quality prevention measures and services; adequate prevention and care information; and safe, effective and affordable medication. The research focused upon this last part. It is interesting to see that this guideline could have included access to care and medication, and not only medication.

The research specifically looked at how governments and other stakeholders have responded to the recommendations and how the community sector has participated in the implementation of one aspect of Guideline 6 - 'safe and effective medication at an affordable price.'

Project Goals:

- To identify successful practices by the Community Sector in creating opportunities to improve access to HIV/AIDS treatment within the framework of the IGHR, particularly Guideline 6.
- Assess the level of dissemination/popularisation of the IGHR at national levels

Project Objectives:

- To identify changes in Government practices post guideline implementation
- To identify changes in community practices post guideline implementation
- To identify community influence in policy making

Method

This project was completed at the end of the year 2001, and the final report was produced in March 2002. The project took 10 months to be completed.

The first stage of the project design was the selection of a sampling of countries. The reason for selecting a subset of countries instead of including all countries was due to time and resource constraints and to keep the project manageable.

Two features of the first-stage sampling were: (1) to ensure that sample countries represent other countries with similar characteristics in the region that were not selected; and (2) to ensure that there is a manageable amount of data. Countries were selected from each major region of the world and in most cases, two organizations or groups per country were invited to participate. When there was a difference in the responses from the same country, follow-up was conducted to clarify the differences. However, not all the NGOs invited accepted, so there are countries with only one response, (eg. Guatemala, Senegal and Venezuela). There are also countries where only one organization was invited (Spain, Poland). Finally, there are also countries where no response was received (Australia, Russia and Yugoslavia). A list of the selected countries has been attached to the report.

Forty organizations were invited to participate, from a total of 21 countries. The questionnaire was completed by 21 organizations (53%) from 15 of 21 countries selected (71%).

NGOs developed their answers to the questionnaire in different ways. For example, one organization in Pakistan called a meeting among other AIDS NGOs to develop a consensus response to the questionnaire. The Canadian HIV/AIDS Legal Network made a bibliographical research of the literature on HIV/AIDS in Canada; the same is the case of FEIM in Argentina. ACCSI from Venezuela answered the questionnaire from their day to day experience. They are currently the leading NGO in Venezuela in issues of access to treatment and have participated fully in negotiations with the pharmaceutical industry. This also applies to Asociación Agua Buena, from Costa Rica.

The questionnaires were returned to the researcher for compilation and comparative analysis. Following the analysis stage, the report was drafted and presented to the advisory committee for additional review and comments.

This project did not attempt to be an exhaustive analysis of the situation of access to treatment in the world, or even in the countries analyzed. Through the questionnaire the project tried to assess the influence of the international guidelines on governmental policies, programs and legislation in relation to access to HIV/AIDS treatment.

Two case studies were featured to illustrate major initiatives and different approaches that the community sector is taking to address

the issues of access to treatment. In addition, the project reviewed relevant literature including web-sites.

How the Results Are Organized

The report has four parts:

1. The first part provides observations on access to treatment in general, and specifically, issues surrounding the applicability of guideline number 6 and related pricing issues.
2. The second part focuses upon two case studies about community actions to improve access to treatment: South Africa and Venezuela. One features community activism (Treatment Access Campaign-TAC) and the other features the use of the court system to access treatment and care.
3. The third part presents an analysis of access to treatment issues in each country, as well as the use of the guidelines by the respondent NGOs to advocate for treatment.
4. The fourth part presents conclusions and a set of recommendations.

OBSERVATIONS FROM THE RESEARCH

Access to Treatment

Recent campaigns, led by local and global NGOs, to increase access to essential drugs in developing countries have brought the human right to health back into the spotlight. Many of these campaigns have focused on increasing access in developing countries to antiretroviral therapies to treat HIV/AIDS. ARV therapies have helped HIV/AIDS in developed countries be treated and managed as a chronic condition.

Tremendous optimism has been generated by the recent developments in combination ARV therapy for HIV/AIDS. There is renewed hope for people living with HIV/AIDS of effective treatment, prolonged survival, reduction of mortality¹ and improvement in quality of life. However, in recent years, there has been considerable discussion of drug pricing and its effect on the ability of people living with HIV/AIDS in developing countries to access drugs used in the treatment of HIV infection and its related conditions.

Of the more than 36 million people living with HIV/AIDS, more than 95% live in the developing world. Today, over one-third of the world's population has no access to essential drugs,² not to mention access to anti-retroviral therapy to treat HIV.³ They do not have access to basic drugs such as painkillers or antibiotics to treat much simpler conditions.

The research project concentrated on access to anti-retroviral therapy. The reason for this is the various challenges posed by this highly effective therapy, among them, the elevated cost of the therapy. Access to anti-retroviral therapy is determined primarily by access to financial resources. The disparity between industrialized and developing countries is highlighted by HIV care and improved quality of life in the former, and relentless increases in HIV-infection and AIDS-related mortality in the latter. Cost of HIV care, as well as treatment, is the most significant factor in this disparity. But there are other factors that can be related to the affordability of ARVs: patents, limited supply, import duties, taxes, and distribution, among others.

¹ In the United States, where ARV treatment has been available since 1996, the new drugs have reduced mortality by up to 90%.

² Médecins Sans Frontières (MSF), What is the MSF Campaign for Access to Essential Medicines? <<http://www.accessmed-msf.org/campaign/campaign.shtm>> (date accessed: December 1st, 2001)

³ As per UNAIDS estimates, less than 10% of PLWAs have access to ARVs. In Africa, less than 1% of those infected receive antiretroviral therapy.

What is the MSF Campaign for Access to Essential Medicines?

Many factors influence access to effective medicines, including: quality of diagnosis; accurate prescribing, selection, distribution and dispensing of medicines; drug quality; capacities of health systems and budgets; lack of research and development (R&D); and price. Through its field projects, MSF is working at the local and national levels to address many of these issues. Internationally, the Campaign is focusing on addressing the lack of R&D, and affordability and availability of effective medicines. MSF website (<http://www.accessmed-msf.org/campaign/campaign.shtm>)

The public profile of the global drug pricing issue has been raised but less attention has been paid to other issues affecting access to treatment, including inadequacies in the health infrastructures of many developing countries. These inadequacies may include:

- a shortage of clinics and hospital beds;
- a shortage of trained health care professionals;
- a lack of laboratory facilities and supplies for diagnostic testing;
- a lack of counsellors pre and post HIV testing;
- a lack of community care infrastructure and/or support;
- a lack of adequate training for health care professionals and laboratory technicians; and
- non-existent or inadequate drug distribution systems.

Poor health infrastructure and difficulties accessing drugs are not unique characteristics of the AIDS pandemic. The care apparatus in most of the developing world is in severe crisis. Typically, health centers and hospitals are short-staffed, facilities for diagnosis are inadequate and there is a lack of drug supplies. In addition, training for health care providers is uneven and often poor. These deficiencies have worsened with the arrival of the HIV epidemic, which simultaneously has increased the demands for health care and reduced the health system's capacity to respond.

The issue of access to treatment for HIV in developing countries is currently of great interest to NGOs, AIDS support groups, the UN system, the media and governments. However, the differences between developed and developing countries are not new.

For years, there has been inadequate access to treatment in the non-industrialized world for diseases including tuberculosis and malaria. Advances in health care in developed countries have had little effect on what is available to the developing world. The HIV pandemic serves to sharpen the awareness of these disparities.

The Human Rights Approach to HIV/AIDS

The human rights approach to HIV/AIDS, as outlined in the International Guidelines on HIV/AIDS and Human Rights, is the most effective approach both in terms of human rights and public health. Over the history of the epidemic there has been growing recognition that without impacting upon human rights, programs cannot successfully impact upon the prevention of HIV and care of people living with HIV/AIDS.

Even though the human rights approach to HIV/AIDS does make both human rights and public health sense, reality has proven more difficult than theory. The human rights approach has succeeded, to some extent, in developed states but not in developing states. One of the reasons for this is the comparative lack of economic resources assigned to public health strategies, such as surveillance, education and prevention programs, accurate diagnosis and treatment in developing countries. This fact, as well as others, will be analyzed further in this thesis. The problem still has not been solved. On the contrary, there are severe human rights concerns related to the AIDS pandemic in developing countries that need to be addressed, such as access to treatment. Countries that defend themselves against the claim that they have violated human rights because of their lack of economic resources are often faced by other large pressing health problems like malaria.

Right to Health

Protecting and promoting human rights is becoming one of the key means of preserving the health of individuals and populations. Under the right to health, the state has certain obligations that are related to the general concept of public health. The main aim of public health is to prevent and control diseases. For this, the public health authorities should – among other things – monitor health status to identify community health problems; inform, educate, and empower people about health issues; and ensure the availability of a competent public health and health care personnel.

Under the right to health, the state has obligations *vis-à-vis* the population. In fact, as the late Jonathan Mann clearly defined them, “the three central functions of public health are: assessing health needs and problems, developing policies designed to address priority health issues, and assuring programs to implement strategic health goals.”⁴

One of the common assertions relating to the implementation of the right to health is the inability of poor countries to provide an adequate level of health care or to provide the economic development which is necessary to achieve an adequate health system. Obstacles to improving the health care system include misallocation of resources and the ineffectual use of them.

There are obligations under the right to health that are not costly and can be taken to improve health status. For example, article 2.1 of the

Twelve of the fifteen countries in the research have included the right to health as a constitutional right.

Although Argentina and Canada have not specifically integrated the right to health as a constitutional right, recognition of the right to health is implied. For example, the Argentinean constitution provides for the constitutional rank of international agreements and pacts, of course including those that refer to the right to health as a human right. In Canada, the right to health is not recognized by the federal government or provinces, with the exception of the province of Quebec. However, other legislation and Canada’s health care system are reflective of a commitment by the governments to ensure that the public is entitled to access to care.

In Venezuela, NGOs estimate that the number of PLWAs is between 500,000 and 800,000, while official numbers reflect another reality, only 3,000. This is also the case in Ghana, Costa Rica, Japan, Spain and Guatemala. On the other hand, the estimates by NGOs and governments in Switzerland and Canada are very similar, reflecting a much more effective surveillance system.

⁴J. Mann, et al, *Health and Human Rights: A Reader* (New York: Routledge, 1999), at 12.

International Covenant on Economic, Social and Cultural Rights (ICESCR) establishes the compromise of States to adopt legislative measures ‘immediately’.⁵ Guideline number 6, in fact, refers to the need for States to enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure availability of safe and effective medication at an affordable price. In this respect, for example, governmental agencies should review the legal framework concerning customs and taxes to maximize access to affordable medication.

But, in order for public health officials to create programs and deliver services, it is necessary that the size of the epidemic be made clear. It is easier to understand why many governments are not paying serious attention to the epidemic when we see the difference in statistics on the number of people with HIV/AIDS presented by international agencies and non governmental organizations (NGOs) on the one hand, and by governmental agencies on the other. Extreme differences, with respect to the ‘official’ data, give poor support to creating programs to respond to the reality.

In general, NGOs’ estimates are much higher. Suggestions to explain this are under-reporting, lack of surveillance or poor administrative tracking. Also, fear of discrimination, stigmatization and human rights violations are issues to be considered. In the Latin American region in general, there is an extreme difference between estimates.

The HIV/AIDS pandemic has changed the perception of the right to health. Access to medical treatment of HIV infection is crucial for the respect of the right to health and the right to life. In Latin America, Brazil is at the forefront of making legislative commitment to access to HIV treatment. This has been due to direct action from PLWA activists complaining about the lack of continuity of drug treatments. South Africa is another example of the involvement of non-governmental organizations in the issue of improving access to treatment.

Access to Treatment as a Human Right?

The preamble of the WHO Constitution establishes the right to health as one of the fundamental human rights. The universal enjoyment of health is related to non-discrimination, the adoption of sanitary and social measures, the promotion and protection of health and the guarantee of the enjoyment of the benefits derived from the

From the 15 countries analyzed, 11 have the right to have access to treatment incorporated as a constitutional right. Some of the countries surveyed (i.e. Ghana) have incorporated the right to have access to treatment through the national legislation, but without constitutional rank. However, such guarantees are not necessarily enforced. Article 38 (d) of the Constitution of the Islamic Republic of Pakistan guarantees the provision of the basic necessities of life, including food, clothing, housing, education and medical relief, to all citizens of the country. Yet, due to financial or resource constraints, rights are left unfulfilled. For instance, ARVs are not available in Pakistan, thus limiting the right to medical relief of PLWAs.

⁵ Under the principle of non-discrimination in arts. 2.2 and 3, States have the obligation to adopt legislative measures –immediately- in order to guarantee the enjoyment of the right in an equal way.

advances of scientific knowledge. One of the main developments stemming from the AIDS pandemic, which resulted from this new discussion about the right to health, is the concept of the 'right to have access to medical treatment'.

For thousands of people living with the disease in the industrialized world, antiretroviral drugs are a miracle, allowing them to lead full, healthy lives. HIV/AIDS can be treated and managed as a chronic condition. The advent of what is known as HAART (Highly Active Anti-Retroviral Therapy) has made an enormous difference.

But at the same time, access to treatment for HIV/AIDS is a challenge because antiretroviral treatment is expensive, difficult to administer, can create drug-resistance and requires a strict individual protocol and reliable psychosocial and material support.

Justice Edwin Cameron, from South Africa's Supreme Court, is openly HIV+ and is taking a drug combination that has restored his health. Cameron told the audience during the XIII International AIDS Conference in Durban, South Africa:

“ I speak of the gap not as an observer or as a commentator, but with intimate personal knowledge. I am an African, proudly an African. I am living with AIDS. I therefore count as one amongst the forbidding statistics of AIDS in Africa. Including the fact that nearly five million South Africans who have the virus.

I speak also of the dread effects of AIDS not as an onlooker. Nearly three years ago, more than twelve years after I had sero-converted, I fell severely ill with the symptomatic effects of HIV. Fortunately for me, I had access to good medical care. After treatment for opportunistic infections that were making me feel sick unto death. Then my doctor started me on combination therapy. Since then, with relatively minor adjustments, I have been privileged to lead a vigorous, healthy, and productive life. I am able to do so because, twice a day, I take two tablets [...]. I can take these tablets because, on the salary of a judge, I am able to afford their cost.

*My presence here embodies the injustices of AIDS in Africa because, on a continent in which 290 million Africans survive on less than one US dollar a day, I can afford monthly medication costs of approximately US\$400 per month. Amidst the poverty of Africa, I stand before you because I am able to purchase health and vigor. I am here because I can pay for life itself.”*⁶

Serious reservations have been raised about the indiscriminate use of ARVs in developing countries, because of these issues of cost, development of resistance, the need for community support and trained personnel and the need to build or strengthen related health infrastructure. Triple therapy is very expensive and the related services required to ensure its safe and effective use are complex.

There is a stark contrast between industrialized countries where patients are usually receiving these treatments through public and private insurance schemes and developing countries where the majority of those requiring treatment cannot access these drugs.

The elevated cost of the therapy impedes access for more than 90% of the population living with HIV/AIDS. Health therefore becomes a privilege of the few and not the right it should be.

⁶ E. Cameron Justice of High Court Of South Africa, "The Deafening Silence Of AIDS" (Plenary Presentation at the XIII International AIDS Conference, Durban, South Africa, 10 July 2000).

Antiretroviral Therapy

The drugs work against the virus through two modes of action:

- *Reverse Transcriptase Inhibitors* (AZT, 3TC, d4T, ddI, ddC, nevirapine and delavirdine).¹ These drugs work by inhibiting or preventing the reverse transcriptase enzyme from converting the genetic material RNA to DNA, an essential step in the life cycle of the virus.
- *Protease Inhibitors* (saquinavir, indinavir, ritonavir and nelfinavir).¹ These work by ‘gumming up’ the chemical scissors which cut up the long RNA chain of proteins and enzymes into the shorter pieces HIV needs to make new copies of itself.

Drug Pricing

Because HIV is a “new” disease, most of the drugs to treat it are still under patent protection. Patent protection has been considered as the main reason for the high cost of ARV therapy. One of the methods of addressing the issue of access to the high-cost ARV treatment has been for governments to use the legal provisions under the TRIPS agreement⁷ to manufacture generic drugs for HIV, without violating patent law. This approach uses a safeguard incorporated into the agreement that protects patent rights, including those for drugs. Patent protection provides an important incentive for innovative research and development of new HIV/AIDS drugs.

However, many of the ARVs are not covered by patent law in all countries. UNAIDS found that generic manufacturers in Argentina, India, Mexico, Spain and Thailand are producing these drugs and exporting them to other countries. This is not the case in Brazil. The private Brazilian manufacturers only supply their national market and do not export their products.⁸

But the TRIPS agreement also foresees that in certain circumstances, such as national emergencies, governments may grant third parties the right to produce and sell a patented product, even without the consent of the patent holder, according to carefully prescribed conditions. This safeguard, known as compulsory licensing,⁹ was incorporated into the TRIPS agreement through negotiations by developing countries. Its maintenance as part of TRIPS has been vigorously defended by NGOs and activist groups, such as Act Up,

In Africa, the markets with the largest capacity to use antiretroviral drugs have lots of patent protection. Everything but Norvir is on patent in South Africa.

Thirty-one countries in Africa have at least one antiretroviral drug under patent. 27 countries have at least 4 antiretroviral drugs under patent.

For example, these are the drugs under patent protection in three African countries:

Ghana (combivir, 3tc, AZT, abacavir, amprenavir, nelfinavir)

Senegal (combivir, 3tc, nevirapine, nelfinavir)

South Africa (combivir, 3tc, ddC, AZT, ddI, d4T, abacavir, delviridine, efavirenz, nevirapine, amprenavir, indinavir, saquinavir, nelfinavir, kaletra)

*Consumer Project on Technology
October 2001*

⁷ Agreement on Trade-Related Aspects of Intellectual property rights, Apr. 15, 1994, Marrakesh Agreement Establishing the World Trade Organization (WTO), Annex 1C, Legal Instruments – Results of the Uruguay Round Vol 31;33 I.L.M. 1197 (1994).

⁸ UNAIDS, WHO, UNICEF, MSF, Sources and prices of selected drugs and diagnostics for people living with HIV/AIDS, May 2001.

⁹ International Council of AIDS Service Organizations (ICASO), Compulsory Licensing and Parallel Importing What do they mean? Will they improve access to essential drugs for people living with HIV/AIDS?

the Consumer Project on Technology, ICASO and Médecins Sans Frontières, who have conducted international campaigns for improved drug access.

In Latin America, Brazil has been the pioneer. Pushed by a robust activist movement¹⁰ and fortunate to have less than 1% of adults infected with HIV, the government has committed to providing ARV drugs for all that need them. Brazil's HIV death rate has been cut in half since the program began four years ago, and hospital admissions for AIDS patients have fallen by 80%. What happened to the price of the drugs is equally striking. Even though Brazil is wealthy compared to many sub-Saharan African nations, the cost of the medications was nearly back-breaking. So, Brazil started making generic versions of several HIV drugs in its own government laboratories. For those drugs with no competition from government-produced generics, the price over the last four years edged down by less than 10%. But for drugs that the government makes, the price of the patented drug tumbled by more than 70% because of the competition. For example, one day's supply of the anti-HIV drug stavudine, costs US\$6.20 in Uganda, almost three dollars off the U.S. price. But in Brazil, where the drug is made by the government, the same dose costs just 56 cents.

- The research illustrates that the prices for a tablet of a treatment drug can vary widely from country to country. For example, compared to the costs of the same drugs in other countries, prices in Japan are exceptionally high.

All Prices in U.S. Dollars

	AZT or ZDV 100 mg tablet	3TC 150 mg tablet	Nevirapine 200 mg tablet
Argentina	\$ 0.14	\$ 0.21	\$ 0.85
Canada	\$ 0.78	\$ 2.85	\$ 3.01
Malaysia	\$ 1.44	\$ 2.37	\$ 3.68
Kenya	\$ 4.85	\$ 1.14	\$ 3.85.
Japan	\$ 3.16	\$ 9.52	\$ 9.43

As per “Sources and Prices of Selected Drugs and Diagnostics for people living with HIV/AIDS” (UNICEF, UNAIDS, WHO and MSF), the median price for these three drugs are:

- AZT (or ZDV) 100 mg tablet: US\$ 0.28
- Nevirapine: 200 mg tablet: US\$ 1.47

¹⁰ Coordenação Nacional de Doenças Sexualmente Transmissíveis e Aids / Ministério da Saúde, Brazil, “*Boletim Epidemiológico de Aids*”, ano XII, número 02 (1999). [translated by author]. In addition, Bernard Pécoul argues that many developing countries do not fully acknowledge patent protection for pharmaceuticals.

Most anti-retroviral medications and other medications for opportunistic infections do not currently have patents granted by the governments of Central American countries and cannot be patented, as they no longer offer NOVELTY. Therefore, these countries are authorized to manufacture generic medicines or to import them from any part of the world, without any infraction of TRIPS or their own national laws.

T W O C A S E S T U D I E S

In addition to activism at the global level, NGOs composed of and working with PLWHAs within individual countries have been mounting efforts to increase access to ARV therapies using arguments informed by the human right to health. These campaigns sometimes involve litigation in national courts in which PLWHAs argue that the government's failure to provide access to ARV therapies violates the right to health enshrined in international and national law. These national cases are important to the international legal discourse on the right to health because they often provide a window on how the right operates at the local level where disease and death ultimately take a toll.

South Africa: An Example of Community Involvement

Life-prolonging and enhancing HIV treatment is available in South Africa. Yet the high prices charged by pharmaceutical companies have put it beyond the reach of the millions who need it. With the current situation, there is a price on human life – a price that millions cannot afford to pay. Nor can the government afford to buy the treatment drugs at retail cost for those who need them. Yet there is hope. A strong civil society advocacy movement has developed to pressure the government into action and to support new initiatives. Today, the country with the highest new HIV infection rates is also the country that the developing world is turning to for leadership in the fight against HIV/AIDS.

South Africa's response to the HIV/AIDS epidemic had a devastatingly slow start. In the chaos of building a post-apartheid country, AIDS was not seen as being a government priority. Although South Africa passed an AIDS prevention plan through cabinet in 1994, it was never implemented.¹¹ As a result of government bureaucracy, the plan was buried and millions of citizens left uninformed and vulnerable. Although wide scale public education campaigns have since begun, it is believed that the preventative measures have been so ineffective that AIDS has spread through South Africa just as quickly as if no preventative measures had been taken.¹² Now, the government faces the additional challenge of making treatment available to those whose infections were not prevented.

The Partnership Against AIDS, a public-private effort involving government, companies, churches and civil society in order to address AIDS was introduced in 1998. The creation of the Partnership recognizes the crucial role civil society has played in combating HIV/AIDS in South Africa. During the government's period of silence on HIV/AIDS, non-governmental organizations, community groups and activists emerged to fill the void by promoting prevention and providing care. Communities responded to the needs of their members with efforts to care for the sick and orphaned. NGOs launched prevention education campaigns and advocated for the treatment and rights of HIV+ persons.

¹¹ "AIDS in the Third World: A Global Disaster." *The Economist* January 2 1999. P.44.

¹² *Ibid.*

The Treatment Action Campaign (TAC) has provided strong leadership among the civil society movement. Founded on December 10, 1998 (International Human Rights Day), TAC's main objective is to campaign for "greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability, and the use of HIV treatments."¹³ TAC has repeatedly called for action from the government to demonstrate strong commitment to combating the HIV/AIDS epidemic. According to Zackie Achmat, TAC Executive Director, South Africa's constitution puts a duty on government to progressively increase the access to healthcare services for all South Africans.¹⁴ TAC has launched several targeted campaigns since its inception to pressure the government to live up to this duty. It has also targeted the pharmaceutical companies to follow through on agreements and to expose excessive profit making.

The Christopher Moraka Defiance Campaign is an example of TAC's advocacy campaigns. Targeted at pharmaceutical companies, the campaign is a unified effort of grassroots activists, civil society organizations and health care professionals. The campaign protested high drug prices through importing generic drugs into South Africa and raising public awareness on pricing issues. The campaign began by requesting Pfizer reduce the costs of its drug flucanazole, which is used to treat opportunistic infections such as thrush and cryptococcal meningitis. At retail, the daily treatment cost exceeds the daily wage of most workers, making it inaccessible to many who would benefit from it. Through the Defiance Campaign, civil society stepped in to protect the right to health, through access to treatment, of South Africans.

The government of South Africa, although not as vocal as civil society, has demonstrated support and commitment for lowering HIV/AIDS drug prices. In 1997, the Medicines and Related Substances Control Act was introduced to allow South Africa to import cheap copies of patented drugs. It was quickly challenged through a lawsuit by the Pharmaceutical Manufacturer's Association of South Africa (PMA) on behalf of 39 international pharmaceutical companies, on the basis that it infringed on their patent rights and ability to make a profit. The lawsuit challenged the mechanisms of parallel importing and compulsory licensing outlined in the Trade Related Aspects of Intellectual Property Rights Agreement. The landmark case was watched closely by governments and civil society around the world, to see what precedent it would set for patent disputes.

Civil society supported the South African government and raised awareness of the necessity of producing or providing cheaper drugs in developing countries that cannot afford the high costs of HIV/AIDS treatment drugs. To show support, March 5 2001 was declared the International Day of Action Against Pharmaceutical Company Profiteering. Demonstrations were organized around the world to protest the lawsuit against the South African government. During the court case, the Treatment Action Campaign was admitted as a friend of the court in order to represent civil society. The court case ended when the lawsuit was withdrawn and the pharmaceutical companies

¹³ Treatment Action Campaign homepage: <http://www.tac.org.za/about.htm>

¹⁴ Ibid.

agreed to pay court costs. It is believed that the negative publicity generated influenced the decision to withdraw. Mark Heywood believes that the victory "...will embolden people in developing countries around the world to stand up for medicines that are affordable."¹⁵ The level of commitment of the South African government will be judged by how effectively the new act is used to make treatment accessible.

South Africa and its government have been the focus of much international attention in the past few years. Prior to the court victory, the XIIIth International AIDS Conference (July 9-14, 2001) hosted in Durban, South Africa and remarks made by President Thabo Mbeki generated debate on access to treatment. Both highlighted the impact of government commitment on accessibility of treatment drugs.

The XIIIth International AIDS Conference marked the first time an African nation had the opportunity to host the conference. As a result, it focussed international attention on the epidemic in Southern Africa. This presented the opportunity for African and other developing nations to share with the world their specific research, successes, obstacles and challenges.¹⁶ It brought the issue of making the treatment that exists in the developed world accessible to the developing world to the forefront of discussions.

South Africa's movement towards accessible treatment has not always been progressive or consistent. President Thabo Mbeki's public questioning of the link between HIV and AIDS resulted in international criticism and public confusion regarding prevention. His reluctance to pay for specialized drugs to fight the disease, such as AZT for HIV+ pregnant women, has done little to increase prevention. Civil society has been quick to respond to such relapses in progress. TAC launched the Mother to Child Transmission Prevention Campaign in response to the government renegeing on its pledge to make AZT available to HIV+ pregnant women.¹⁷ As a result of the pressure, prevention programs have now been launched in 18 government hospitals. Although not as comprehensive as it needs to be, the program is a step forward.

Today, South Africa has a prominent role to play in regards to access to treatment. This is due to strong advocacy efforts by civil society, increased government commitment and recent events spotlighting the crisis in South Africa. Effective HIV/AIDS prevention and treatment is dependent on strong government commitment. As thus seen in South Africa, communities and civil society can have a positive impact on access to treatment through alternatively pressuring and supporting the government. International attention is now drawn to South Africa to see how government and civil society will work together to improve access to treatment, as important precedents are being established, which will impact the rest of the world.

¹⁵ Catherine Roberts "The Forgotten" *Macleans* April 30, 2001.

¹⁶ Debora Ewing, *The Natal Witness* May 3 2001.

¹⁷ Treatment Action Campaign homepage: <http://www.tac.org.za>

Latin America: An Example of the Use of Courts to Gain Access to Treatment and Care

Despite the fairly progressive developments in the realization and protection of human rights at the international level and the existence of an evolving framework on the regional front, the essential point of such activity must be to influence and transform the domestic context. Human rights have to be implemented first and foremost at national and local levels. The primary responsibility of States to realize human rights is *vis-à-vis* the people who live under the jurisdiction of these States.

The AIDS epidemic has created a new method of litigation in national courts regarding economic and social rights. In almost every country in Latin America, governments have been taken to court by PLWAs claiming their right to have access to HIV treatment. And in every occasion the courts have granted the plaintiffs claim and have ordered the governments to provide ARV therapy free of charge. In Costa Rica, for example, almost 600 patients are now taking the medications¹⁸ and figures released by the Health Ministry reveal a drop of in the mortality rate of 60%-- from 102 deaths in 1997 before triple therapy to 44 deaths in 1998 with triple therapy-- even though the number of diagnosed cases increased.

In Mexico, the Supreme Court ordered the *Instituto Mexicano del Seguro Social* (IMSS) (the Social Security Institute) to provide to all the patients from public hospitals, the necessary medical treatment to treat “any disease, no matter what it is.”¹⁹ ARVs are not included in the ‘basic catalogue of medicines’. In order for the government to provide treatment free of charge, such treatment has to be included in this catalogue.

The Mexican Supreme Court interpreted the right to health as inclusive of the right to have access to basic medicaments to treat the disease. The Court decided that the right to the protection of health includes the right of the individual to receive, from the public health authorities, the basic medical treatment for the disease. The Court continued its decision, holding that it does not matter if the medicines are of recent discovery and development or that there are other diseases that need equal or more attention, because those are questions outside the right of the individual to receive basic treatment for the disease.

One step further was taken by PLWAs in El Salvador. After introducing a *acción de amparo* in the Supreme Court to have their right to health respected by government authorities who have denied treatment to HIV+ individuals and, getting no answer, they decided to go to the Inter American Commission on Human Rights. In February 2000, the Commission ordered the government of El Salvador to supply antiretroviral medications to 26 Salvadorans who filed a petition in September 1999.²⁰

¹⁸ The Costa Rican government provides anti-retroviral medications to all 600 patients who currently need it. See Richard Stern, AIDS in the Developing World: Lessons from the Central American experience, online: <<ftp://lists.inet.co.th/pub/sea-aids/care/care99.txt>> (date accessed: September 15, 2000).

¹⁹ *José Luis Castro Ramírez v. Instituto Mexicano del Seguro Social*, Tribunal Pleno, Suprema Corte de Justicia, amparo 223/97, Novena Epoca Instancia: Pleno Fuente: Semanario Judicial de la Federación y su Gaceta Tomo: XI, Marzo de 2000 Tesis: P. XIX/2000 Pg. 112, Materia: Constitucional Tesis aislada, online: (http://www.scjn.gob.mx/Consultas/Inicial_Consultas.asp) date accessed: September 24, 2000.

²⁰ *Jorge Odir Miranda v. El Gobierno de El Salvador*, Inter American Commission on Human Rights, Organization of American States, Washington DC, February, 2000. Case Number 12.249.

However, the Salvadorian government figured that it is cheaper to not give medications, which would cost \$700 monthly than to have to face the "consequences" which might be imposed by the Commission. In fact, the Commission seems completely impotent in the face of the Salvadoran's government's intransigence.

In 1999 the Supreme Court of Venezuela established that the Ministry of Health was in violation of the right to health, the right to life and the right to have access to scientific advances under the Venezuelan Constitution. The Court ordered the Minister to provide antiretroviral medications, treatments for opportunistic infections, and diagnostic testing – all free of charge -- to all people with HIV/AIDS living in Venezuela. The Court also ordered the Ministry to develop HIV/AIDS prevention and education campaigns.

In the region, using the court system is the only way that PLWAs have had to try and gain access to medical treatment. Some have died in the meantime. Where success was achieved, lives have been saved. However, success has ultimately depended on the governments responding to court orders which some have ignored.

RESULTS : SITUATION BY COUNTRY

CANADA

Right to Health & Essential Drugs List

Although Canada has a universal health-care system and all provincial systems provide universal access, there is no explicit legal recognition of the right to health care. The exception is the province of Québec, where section 4 of the Act Respecting Health Services and Social Services provides that “[e]very person has the right to receive adequate, continuous and personal health services from a scientific, human and social standpoint, taking into account the organization and resources within the establishment providing such services.” (S.Q., 1991, c. 42). However, other legislation in Québec and other provinces, while not establishing rights to health care and treatment, is evidence of a commitment by the governments to ensure that the public is entitled to access care. Access to treatment is not recognized as part of the right to health.

The Canada Health Act (1985) establishes and defines universal access to insured health services, replacing previous legislation first enacted in 1964. At the provincial level the year enacted varies by province/territory.

Each province/territory maintains its own Essential Drugs List, inclusion of HIV/AIDS treatments varies by province. For example, AZT was approved by the federal government in 1986 and was made available to AIDS patients free of charge starting that year in all provinces except British Columbia (until 1991).

Access to Treatment

The public sector provides treatment for 60-80% of PLWAs. In order to qualify for social and public insurance benefits a person must be a Canadian citizen, landed immigrant, permanent resident or be granted refugee status. Provinces usually require several months residency before insured health services will be provided. Treatment available through the public health sector includes: treatment for STDs; treatment for opportunistic infections (including TB); triple therapy, new and emerging treatments; protease inhibitors; NNRT; palliative care; and, nutritional supplements. With some exceptions, the provinces provide drugs used in the treatment of HIV/AIDS free of charge. However, there is often a reluctance to add new drugs to provincial plans. Considerable differences exist among the provinces in terms of which new drugs are made available through provincial plans and how quickly they are made available. It is important to note

that public health insurance plans in each province/territory cover ‘medically necessary’ services provided by doctors and hospitals, but do not cover prescription drugs other than those provided in hospital (except in British Columbia).

However, a patchwork of supplementary public plans provide coverage for prescription drugs for some people (eg, elderly, social assistance recipients) under some conditions, including in some cases plans that partially cover the costs of people with some

"catastrophically" high drug costs (which plans are geared-to-income and usually require the exhaustion of a deductible before coverage kicks in). This is the case of the Trillium Program in the province of Ontario, which is geared to the person's income, requiring them to pay a deductible amount (based on their income), and after that point, drugs costs beyond that are covered by the program.

In the past five years there have been specific programs to benefit the following target groups: pregnant women; children; MSM; IDU; migrants; employed persons; sex workers and Aboriginal communities. The federal government's Canadian AIDS Strategy (renewed, 1997) and most provincial AIDS strategies recognize, at least in principle, the vulnerability of marginalized and disenfranchised groups to HIV/AIDS and the barriers that marginalization poses for access to treatment.

It is estimated that 20-40% of PLWAs in Canada receive treatment through the private sector. Private insurance companies will typically cover expenses if the person had already purchased coverage prior to a diagnosis of HIV-positive status. Most will not sell insurance if HIV-positive status is already known, or will only cover the cost of health care not related to HIV/AIDS. Private insurance covers hospitalization, blood tests and medications. It typically covers the cost of medications as well as items not covered by provincial health insurance plans (such as private hospital rooms). However, many private insurers limit total annual claims for medication to a set amount, such as \$2000.

Government & Pharmaceuticals

The government of Canada obtains ARVs through purchasing them directly from the pharmaceutical industry and through generic manufacturing. Canada has not been involved in direct negotiations with pharmaceutical companies.

Community Role

Although there is still much progress to be made, the past five years have seen increasing consolidation of community-based initiatives and increasing consolidation by governments with community and activist stakeholders. The Canadian HIV/AIDS Legal Network has filled an important "advocacy" gap in developing legal, ethical and policy analyses of key and emerging HIV/AIDS issues, including those relating to access to treatment. Close collaboration on advocacy among organizations such as the Legal Network, CATIE, CTAC, CAAN and others has increased community-based capacity to lobby governments for improved policies and programs. Such lobbying, for example, was an important factor in the federal government's renewal of the Canadian AIDS Strategy in 1997, as well as the federal government's decision in 1998 to begin a review and modernization of the drug regulation and approval process. Sustained political pressure from community advocates has meant that access to novel AIDS therapies through compassionate access or emergency drug-release programs had become standard by 1996. Essentially, improvements in access to treatment are the results of strong lobbying and advocacy by communities, adoption of new legislation, and community-based access initiatives.

International Guidelines

The Canadian HIV/AIDS Legal Network (CHALN) has interacted with the government in improving access to treatment for PLWAs. This has been done through lobbying governments and pharmaceutical companies, meetings with government authorities and extensive collaboration with other organizations and activists. CHALN was aware of the International Guidelines as the Executive Director was involved in drafting them. CHALN has actively promoted the guidelines through articles in their publications and refers to them in reports. The IG are included as a reference in the Network's mission statement.

The Canadian AIDS Society (CAS) interacts with the government through lobbying governments, lobbying pharmaceutical companies, meetings with governmental authorities and street mobilizations, in order to improve access to treatment. The International Guidelines are an important lobbying tool and point of reference for advocacy to address injustices within Canada, such as the impact of HIV/AIDS on Aboriginal communities. The Canadian government has not incorporated the guidelines into national legislation. References to the IG in governmental documents are rare, but an example can be found in Canadian International Development Agency's (CIDA) HIV/AIDS Action Plan and Health Canada's "Case for Canadians to Act Globally."

In the past five years, government policies have tended to become more restrictive in the area of access to treatment. The availability of new treatments have led governments and public health authorities to consider HIV/AIDS as a treatable disease like any other, neglecting the fact that, to a disproportionate and unacceptable extent, it continues to affect the most marginalized people in Canadian society. The adoption of the International Guidelines has not influenced the Canadian government in the area of treatment. However the IG may have made some difference in how the government has responded to immigration issues and prison issues.

COSTA RICA

Right to Health & Essential Drugs List

The right to health is guaranteed in Costa Rica's Political Constitution of 1949, Articles 21 and 70. Access to treatment is included as a component as the right to health through Article 7 of the General Law on HIV/AIDS. HIV/AIDS treatment was included in Costa Rica's Essential Drugs List in 1997.

Access to Treatment

The majority of PLWAs, over eighty percent, access treatment through the public sector. Access to the Costa Rican Social Security System is guaranteed to all inhabitants. However, a percentage of an individual's wages should be contributed to the system, and added to by the employer and the State. Individuals who lack economic resources or undocumented immigrants are able to access health services through special systems of insurance that are assumed by the state. The treatment that is available through the public sector includes: treatment for STDs; treatment for opportunistic infections,

including TB; triple therapy; palliative care; and, nutritional supplements. The public sector offers integral attention and comprehensive treatment to patients with HIV infection. However, psychological support for patients and their families is scarce.

In the past five years there have been several specific programs to benefit certain target groups. Targeted groups have included: pregnant women; children; men who have sex with men; sex workers; and, individuals who are at higher risk due to occupational hazards. Improvements in access to treatment have been the result of: strong lobbying and advocacy by communities; adoption of new legislation; and, community-based access initiatives.

Very few PLWAs receive treatment through the private sector. It is estimated that one percent receive personal private drug donations and that five percent buy treatment drugs directly from a pharmacy. Private insurance companies do not cover any expenses related to HIV/AIDS.

Government and Pharmaceuticals

The government of Costa Rica is considering generic production as a means to lower the cost of HIV/AIDS treatment drugs. In addition, there have been direct negotiations with pharmaceutical companies to lower the costs of all ARVs. Merck Sharp and Dohme, Glaxo and Roche have been approached to lower the prices by fifty percent.

Community Role

Fundación Vida (Life Foundation) has interacted with the government to increase access to treatment. They have done so by: lobbying governments; lobbying pharmaceutical companies; initiating lawsuits; meeting with governmental authorities; lobbying the local hospital; and, media campaigns.

International Guidelines

Fundación Vida was informed of the International Guidelines through information posted on the UNAIDS web page. However, the guidelines have not been incorporated into advocacy efforts, as it is believed that advocacy through the legal system is sufficient to attain treatment goals. The Costa Rican government has incorporated the guidelines into national legislation. The General Law of HIV/AIDS incorporates elements of protection of human rights, State obligations, community participation and other elements of the guidelines. How the guidelines have influenced the State is unknown, but the respondent believes that the State has shown little interest in popularizing the guidelines.

In the last five years government policies have become more cohesive. The public health and the Social Security systems are entering the final stage of a restructuring of the health sector. The Costa Rican Social Security system now fields correspondence regarding illness prevention, instead of the Ministry of Health. Respect for the rights of the users of health services has begun to be institutionalized, and communities have become integrated into decision-making processes.

GHANA

Right to Health & Essential Drugs List

The right to health has been recognized in Ghana's Constitution since Article 24 was implemented in 1992. Access to treatment is not stated categorically but is implied. Ghana's Essential Drug's List does not cover HIV/AIDS treatment.

Access to Treatment

The public health sector provides treatment to less than 1% of PLWAs, through a pilot project. To qualify for these social and public insurance benefits, an individual must contribute to the scheme. The treatment available includes: treatment for STDs; treatment for opportunistic infections, including TB; mono therapy; double/bi therapy; triple therapy; protease inhibitors; palliative care; and, nutritional supplements.

Other than through this pilot, ARVs are not available at government/ public health institutions. In the past five years, there have been specific programs to benefit all members of society, including STD treatment for sex workers. There have been improvements in access to treatment. However, even though ARVs are now available (at pharmacies), the high cost of these drugs puts them beyond the reach of most patients.

The majority of PLWAs make their own arrangements for treatment. Most PLWAs depend on traditional herbal medicine, most of which is not tested for efficacy and safety. The private sector does not cover treatment for HIV/AIDS.

Government & Pharmaceuticals

The government of Ghana is not in negotiations with pharmaceutical companies to lower the prices and make ARVs more available to the population.

Community Participation

The Ghana HIV/AIDS Network has interacted with the government to improve access to treatment through lobbying and meetings with government authorities. It also advocates for pharmaceutical companies to allow parallel imports through press publications and email campaigns. Prolink interacts with the government to increase access to treatment through lobbying the government and meeting with officials.

International Guidelines

The Ghana HIV/AIDS Network was aware of the International Guidelines through UNAIDS publications but has not yet applied them to advocacy work. Prolink was unaware of the International Guidelines and has not incorporated them into advocacy efforts.

There have been several positive changes in government policies in the last five years to structure a more comprehensive national response to HIV/AIDS. In 1999, the government issued a communiqué after the International Partnership against AIDS in Africa consultation to establish a program for social mobilization against AIDS. A supra-ministerial and multi-sector body involving all government ministries, the private

sector and non-governmental organizations was established to combat HIV/AIDS. The National AIDS Control Programme (NACP) issued a draft national STD/HIV/AIDS policy in August 2000, which advocated against discrimination and stigmatization of PLWAs. In addition, the Ghana AIDS Commission was created, with the President as chairman, to coordinate the national AIDS response. The International Guidelines have not been incorporated or referred to in governmental policy changes.

GUATEMALA

Right to Health & Essential Drugs List

The right to health is recognized in Articles 93-95 of the Political Constitution of the Republic of Guatemala (May 1985). The government is currently in discussions with civil society regarding Decree n 27-2000-06-26, which would ensure access to HIV/AIDS treatment. HIV/AIDS treatment is not included in Guatemala's Essential Drugs List.

Access to Treatment

The public sector provides treatment for an estimated 10-30% of PLWAs. The treatment available includes: treatment for STDs; opportunistic infections (if hospitalized) including TB; and, mono therapy in terms of AZT for pregnant women. Triple therapy and nutritional supplements are covered through the Social Security System. Undocumented immigrants/migrants have access to government-run health programs. The Social Security System provides up-to-date HIV/AIDS treatment. In two Ministry of Health hospitals there are patients who are receiving ARV treatment paid for by research and NGO donations. However, many patients' opportunistic infections remain untreated due to a lack of skilled medical staff.

There have been specific programs targeted to benefit pregnant women and government employees. However, both provide very low coverage.

There has been a marked improvement in access to treatment and care in Guatemala during the past five years. The Social Security System was initiated in 1997. It provides benefits to workers of formal enterprises that comprise more than three employees. Nine departments out of twenty-three are eligible for common disease coverage, the remainder are only covered for accidents. The Ministry of Health system formally covers everyone, including foreigners, although the actual coverage is quite low. The quality of services and resources is poor, particularly in rural areas. However, the quality has greatly improved since 1999. In 2000 there was a large increase in coverage regarding ARVs and over 1000 people are receiving treatment. Improvements in access to treatment have been influenced by pharmaceutical company donations and community-based access initiatives.

Very little treatment is accessible through the private sector. 1.5% of PLWAs receive drug donations from pharmaceutical companies, 2% from foundations and 1.5% buy directly from a pharmacy. Private insurance plans do not cover any expenses related to

HIV/AIDS except for HIV testing. There have been no changes in private health insurance legislation in the past five years.

Government & Pharmaceuticals

The Social Security System obtains ARVs through purchasing them directly from the pharmaceutical industry and manufacturing generic drugs. The government has been in negotiations with the pharmaceutical industry to reduce the costs of drugs and has expressed willingness to import low cost drugs in cooperation with civil society. It is attempting to introduce drugs at low cost and then make the patients or other donors pay for them. The problem faced is that many of the people depending on the Ministry of Health System comprise the poorest segment of the population and do not have the means to pay.

As a result of the negotiations, Merck has already approved a price reduction of 95% for Indinavir and Efavirenz. Therefore, Indinavir will cost US\$ 600 per person per year while Efavirenz will cost US\$ 500 per person per year. The government is also interested in the Brazilian state production and in Indian generic producers such as CIPLA. Community participation Médicos Sin Fronteras (MSF) interacts with the government in increasing access to treatment for PLWAs through lobbying government and pharmaceutical companies, meetings with government authorities and street mobilizations. MSF provides financial help to PLWA groups and technical advice to NGOs and government.

International Guidelines

MSF is aware of the International Guidelines and has used general concepts about human rights that are included in the Guidelines, but the guidelines have not been used formally as support documents. MSF finds the guidelines useful as a background document to orient action but not as a direct tool.

The government of Guatemala has incorporated the International Guidelines into national legislation through Decree 27-2000-06-26. Politicians such as Zury Rios, promoter of the AIDS Law and FRG member, are familiar with the International Guidelines and have used them to push for AIDS legislation.

Changes in accessing treatment have been moving slowly, often without supportive legislation or action. However, there have been many noticeable improvements. The Ministry of Health has moved AIDS up on its priority scale and has agreed to introduce the syndromatic approach to treat STDs. The law 27/2000 was enacted to protect the human rights of people living with HIV/AIDS. The National AIDS Program has expressed concern over the ARVs supply and an AZT treatment program has been introduced for pregnant women. Strong barriers to condom promotion are slowly fading away and there has been a significant improvement in the AIDS reporting system.

JAPAN

Right to Health & Essential Drug List

The right to health has been recognized in the Japanese Constitution since 1947 (Ch. 3, Art. 25). The New Legislation for Prevention and Treatment of Infectious Diseases was implemented in 1999 to ensure access to HIV/AIDS treatment. HIV/AIDS treatment is included in Japan's Essential Drug List. AZT was first introduced on the list in 1987.

Access to Treatment

Over 80% of PLWAs in Japan access treatment through the public health system, which is available to Japanese nationals and documented migrant workers. Available treatment includes: treatment for STDs; treatment for opportunistic infections (including TB); double/bi therapy; triple therapy; protease inhibitors; NNRT; palliative care; and, nutritional supplements.

There have been no specific programs to benefit specific target groups in the past five years. After a political settlement between the government and a PLWA with hemophilia in 1996, new legislation was introduced to ensure access to treatment and provide welfare benefits to PLWAs as disabled persons. The improvements in access to treatment are due to strong political commitment, strong lobbying and advocacy by communities, adoption of new legislation and International Guidelines.

Very few people receive treatment through the private sector. Foreigners without documents or insurance must access treatment through the private sector. Some Japanese PLWAs prefer to out of fear that their HIV status will be publicly disclosed if they use the public system. Private insurance companies cover hospitalization expenses. There have been no changes to private health insurance legislation regarding HIV/AIDS in the past 5 years.

Government and Pharmaceuticals

The Japanese government obtains ARVs through purchasing them directly from the pharmaceutical industry and importing. The government of Japan has not engaged in direct negotiations with pharmaceutical companies.

Community Participation

PLACE Tokyo interacts with the government to improve access to treatment through lobbying and regular meetings with government authorities.

International Guidelines

PLACE Tokyo was aware of the guidelines through promotions by UNAIDS and ICASO. It has used the guidelines to advocate for improved access to treatment and is translating them to Japanese. The guidelines are useful in establishing international standards that are supportive for the right to health, especially for migrant people. In 1996 new legislation stated the importance of recognizing human rights in terms of prevention and care, which covers infectious diseases such as HIV/AIDS. The legislation recognizes PLWAs as disabled persons, and therefore, most of the medical cost of HIV/AIDS treatment is covered by the public health system. The International

Guidelines have been influential on the government of Japan. In 1999, the Minister of Health and Welfare added human rights issues to its research project on HIV/AIDS.

KENYA

Right to Health & Essential Drugs List

The right to health is recognized in articles 70-85 of the constitution of Kenya. Access to treatment is recognized as an element of the right to health in the constitution and the Universal Declaration of Human Rights, of which Kenya is a signatory. However, there are no legal provisions to support this recognition and HIV/AIDS treatment drugs are not included in Kenya's Essential Drugs List.

Access to Treatment

Treatment available through the public health system includes: treatment for STDs; treatment for opportunistic infections (including TB); palliative care; and, nutritional supplements.

Specific programs have been initiated to benefit pregnant women, children, students, government employees and employed persons.

There has been no marked improvement in access to treatment in the last five years.

Private insurance companies do not cover expenses related to HIV/AIDS. However, a few large companies have introduced a system where a person is covered up to a certain fixed amount of money regardless of their HIV status. This fee covers hospitalization, visits to the doctor, blood tests and medication. In the past five years there have been no legislative changes regarding private health insurance and HIV/AIDS. However, changes have come about due to sensitization of insurance companies by civil society organizations.

Government and Pharmaceuticals

The government of Kenya is considering negotiation with pharmaceutical companies and parallel importing to reduce the costs of medications.

International Guidelines

The Kenya AIDS NGOs Consortium is aware of the International Guidelines through WHO, UNDP and attending international conferences. It uses the guidelines in various sensitization lectures to the army, police, hospitals, and employers. The Kenya Ethical and Legal Network (KELIN) uses the guidelines to advocate ethical-legal issues of HIV/AIDS. The guidelines are a useful tool for accessing treatment as due to the absence of legislation, they provide the only source of rules and guidelines on ethical issues in the country.

The government has not incorporated the International Guidelines into national legislation. However, the IG are referenced in the Strategic Plan of the National AIDS Control Council.

MALAYSIA

Right to Health & Essential Drugs List

The right to health care is not recognized in Malaysia's constitution. There are no existing provisions at national or provincial/state level to ensure access to treatment. HIV/AIDS treatment drugs are not included on Malaysia's Essential Drugs List.

Access to Treatment

Less than 10% of PLWAs in Malaysia access treatment through the public health sector, although all citizens are eligible for social and public insurance benefits. Treatment available through the public health sector includes treatment for STDs; treatment for opportunistic infections (including TB); Mono therapy; double/bi therapy; protease inhibitors, NNRT, palliative care, nutritional supplements and alternative treatments.

In the past five years, specific programs have been initiated to benefit target groups of pregnant women, mothers, children and health care workers.

Improvements in access to treatment are due to strong lobbying and advocacy by communities in addition to reduced drug prices

Private insurance companies cover expenses related to HIV/AIDS if the specific insurance plan, 38 Critical Illnesses Plan, has been purchased. It is a medical plan designed to cover 38 listed major illnesses. It includes HIV/AIDS in the following context:

- HIV infection from blood transfusion in Malaysia, Singapore or Brunei
- Occupationally Acquired HIV infection. A strict criteria is set to ascertain if the infection had been occupationally transmitted.
- Full blown AIDS (according to their definition) where criteria includes CD4 less than 200 and evidence of OI or AIDS related tumors.

There have been no changes in private health insurance legislation regarding HIV/AIDS in the past five years.

Government and Pharmaceuticals

The government of Malaysia obtains ARVs through purchasing them directly from the pharmaceutical industry and importing. The government has been in direct negotiations with the pharmaceutical industry in order to lower the cost of medications.

Community Participation

The Malaysian AIDS Council (MAC) has interacted with the government in efforts to increase access to treatment for PLWAs. Initiatives have included lobbying governments, lobbying pharmaceutical companies and meetings with governmental authorities.

International Guidelines

MAC was aware of the International Guidelines due to the effective promotion of them by the Asia Pacific Council of AIDS Service Organizations (APCASO). MAC has used the guidelines to advocate for access to treatment but is not aware of any use by the government. Improvements in government policies in the past five years have included antenatal screening and limited treatment, including treatment for children. The Malaysian government has not been influenced by adoption of the International Guidelines.

The NETHERLANDS

Right to Health & Essential Drugs List

The right to health is recognized in articles 22 and 36 of the Netherlands' Constitution. Access to treatment is considered as part of that right and HIV/AIDS treatment has been included in the Essential Drug's List since 1996. In addition, there are legal provisions at the national level to further ensure access to HIV/AIDS treatment.

Access to Treatment

The public sector provides treatment for over eighty percent of the PLWAs. The treatment available through the public health system includes: treatment for STDs; treatment for opportunistic infections, including TB; double/bi therapy; triple therapy; protease inhibitors; NNRT; palliative care; and, nutritional supplements.

In the past five years there have been specific programs to benefit men who have sex with men, injection drug users, sex workers and immigrant populations. Improvements in access to treatment have been the result of strong lobbying and advocacy by communities, as well as strong political commitment and leadership.

Government & Pharmaceuticals

The government of the Netherlands buys ARVs directly from the pharmaceutical industry. It has not been considering using other approaches, such as parallel importing, to lower the costs of ARVs.

International Guidelines

The non governmental organization, STOP AIDS NOW!, was not aware of the existence of the International Guidelines. Therefore, the guidelines have not been incorporated into their advocacy work. STOP AIDS NOW! does not believe that the guidelines have influenced the government in any way.

The main change in government policies in the last five years is that ARVs are now provided free of charge to anyone who needs them, through the national health insurance system.

PAKISTAN

Right to Health & Essential Drugs List

The right to health is recognized in Article 38 (d) of the Constitution of the Islamic Republic of Pakistan. There are no legal provisions to ensure access to treatment. With the exception of treatment for opportunistic infections, HIV/AIDS treatment is not included in Pakistan's Essential Drugs List.

Access to Treatment

10-30% of PLWAs receive treatment through the public sector. Treatment covered under the public system includes: treatment for STDs; and, treatment for opportunistic infections, including TB. ARVs are not available in Pakistan.

Programs and initiatives in the last five years have focused on the general population. There have been specific programs for IDU, migrants and government employees.

The Government of Pakistan is making concrete efforts to overcome the problem of HIV/AIDS in the country and to provide access to treatment and care within the available resources. Improvements in access to treatment have been due to strong lobbying/advocacy by communities and community-based initiatives. Cheaper drug prices have also been seen for opportunistic infections. 5% of PLWAs buy treatment drugs through the pharmacy at their own expense.

Government and Pharmaceuticals

The government does not obtain ARVs, they are currently unavailable in Pakistan. The government has not been involved in negotiations with pharmaceutical companies for ARVs. However, it has managed a 5-10% reduction in the price of drugs to treat opportunistic infections.

Community Participation

The AIDS Prevention Society of Pakistan (APSOP) has interacted with the government through lobbying government and pharmaceutical companies, meeting with government authorities and street mobilizations. The Pakistan AIDS Prevention Society is involved with lobbying the government and motivating the network for action.

International Guidelines

The respondents were aware of the International Guidelines through electronic and printed matter from sources such as APCASO and UNAIDS, and are aware of other organizations which also use the guidelines. The guidelines are useful for outlining a uniform approach to take with advocacy. They explain the concept of human rights, how it applies to HIV/AIDS and provides practical advice on how to apply them.

The government of Pakistan has not incorporated the International Guidelines into national legislation. However, policies on Blood Banks and the AIDS Control Program reflect a human rights approach. There is no direct mention of the guidelines in government documents.

The respondents believe the government has made positive changes, even with large obstacles in the way of progress. Government constraints include a lack of financial resources and religious pressure. It is believed that the government of Pakistan has been influenced by the guidelines to some extent.

POLAND

Right to Health & Essential Drugs List

Poland's constitution recognizes the right to health. There are legal provisions at both national and provincial levels to ensure access to HIV/AIDS treatment in the 1996 National Plan. Poland has an Essential Drugs List. Whether HIV treatment is included is not known.

Access to Treatment

The public sector is the sector that deals with AIDS expenses, through it over 80% of PLWAs receive treatment. The treatment available includes: treatment for STDs; opportunistic infections (including TB); triple therapy; protease inhibitors; NNRT; palliative care; and, nutritional supplements.

The government of Poland has initiated programs to specifically benefit pregnant women and children. Improvements in access to treatment and care in the last five years are largely due to strong political commitment/leadership, strong lobbying and advocacy by communities, donations of drug companies and the International Guidelines.

Government and Pharmaceuticals

The government of Poland obtains ARVs through purchasing them directly from the pharmaceutical industry. The government has been involved in direct negotiations with all producers in the pharmaceutical industry to reduce costs. It is estimated that the drugs will cost \$8,750.00 - \$12,500.00 per person annually.

Community Participation

Stowazyszenie Wolontariuszy Wobec AIDS "Badz z nami" has interacted with the government in improving access to treatment for PLWAs. Its activities have focussed on lobbying the government and pharmaceutical companies, meetings with governmental authorities, street mobilizations and producing publications.

International Guidelines

Stowazyszenie Wolontariuszy Wobec AIDS "Badz z nami" was aware of the International Guidelines through ICASO and UNAIDS. Although they have not incorporated them into advocacy initiatives they find the guidelines to be comprehensive and useful. The guidelines have been incorporated into national legislation and are referenced in government documents.

Poland has been in the process of implementing a comprehensive National Plan since 1996. The plan has identified guaranteed access to care and medical treatment for

PLWAs as a priority. The International Guidelines have had a positive influence on the government of Poland.

SENEGAL

Right to Health & Essential Drugs List

The right to health has been recognized in the constitution of Senegal since Independence in 1963. Legal provisions have been established to ensure access to treatment since the 1980s. However they do not deal specifically with HIV/AIDS. Although HIV/AIDS treatment drugs are not specifically identified in Senegal's Essential Drugs List, they have been considered in special circumstances since 1998.

Access to Treatment

10-30% of PLWAs receive treatment through the public sector. The treatment available includes: treatment for STDs; opportunistic infections (including TB); and, occasionally nutritional supplements. In addition, double/bi therapy, protease inhibitors and NNRT are available. In August of 1998, the government established a national initiative for access to antiretroviral therapies (ISAARVS) which currently benefits 160 individuals.

In the last five years there have been specific programs targeted to benefit pregnant women and children in order to reduce the prevalence of mother to child transmission (MTCT). There are also programs that focus on sex workers.

Improvements in access to treatment have been due to strong political commitment/leadership, strong lobbying/advocacy by communities, cheaper drug prices, the International Guidelines and community-based access initiatives.

Whether private insurance companies cover expenses related to HIV/AIDS (and the type of expenses covered) is dependant on the policy purchased. There have been no changes in private health insurance legislation regarding HIV/AIDS in the past five years. It is estimated that 10% of PLWAs have received private drug donations through pharmaceutical companies. (Fond de Solidarite Therapeutic International, France and Agence National de Research Scientific.)

Governments and Pharmaceuticals

The government of Senegal obtains ARVs through purchasing them directly from pharmaceutical companies and importing. The government has negotiated directly with the pharmaceutical companies Merck Sharp and Dohme, Glaxo Smith Kline, Bristol-Myers Squibb, Boehringer Ingelheim and Roche. As a result, the prices of drugs such as retrovir, combivir, crivivan, epivir, videx and zertiv have been reduced by 85-90%, bringing them down to an average annual cost of US\$ 1000 per person.

Community Participation

The African Council of AIDS Service Organizations (AfriCASO) has interacted with the government through lobbying both the government and pharmaceutical companies and meeting with government officials.

International Guidelines

As a focal point for distribution, AfriCASO is very familiar with the International Guidelines. AfriCASO provides training on the guidelines and distributes them for use by NGOs and PLWA groups as a tool towards advocating for access to treatment. AfriCASO has found the guidelines useful in providing guidance in lobbying for treatment.

The Senegalese government has incorporated the principles of the guidelines in national legislation and refers to them in national documents, such as the 'Guide de Reference pour prise en charge PIVVs' (March 2001).

There have been several changes in government policies in the last five years, indicating an increase in political commitment. Senegalese leaders, including the President, have been advocating through African governments to make HIV/AIDS a priority issue on the continent through initiatives such as 'Africa helps Africa.' The government has implemented a large training program for health professionals in terms of HIV/AIDS counseling and ethics, established the ISAAV, and has been involved in negotiations with pharmaceutical companies.

The International Guidelines have influenced leaders by providing them with guidelines to work within for advocacy and lobbying purposes.

SPAIN

Right to Health & Essential Drugs List

The Spanish Constitution of 1978 recognizes the right to health in Articles 43 and 49. Access to treatment is recognized as a part of the right to health and HIV/AIDS treatment is included in the Essential Drugs List. AZT was introduced to the list in 1987, ddI and ddc were introduced in 1992, and other antiretroviral therapies are added as they gain approval.

Access to Treatment

Over eighty percent of PLWAs receive treatment through the public sector. All residents of Spain are entitled to qualify for social and public health insurance and receive public health insurance as long as their papers and documents are in order. Treatment available through the public sector includes: treatment for STDs; treatment for opportunistic infections, including TB; triple therapy; protease inhibitors; NNRT; palliative care; and, nutritional supplements.

In the past five years there have been specific programs to benefit: pregnant women; children; men who have sex with men; intravenous drug users; migrants; and, sex workers. Access to treatment has improved due to the availability of more efficient blood test to monitor HIV and increased pharmacotherapy. The improvements have been the result of the adoption of new legislation, the International Guidelines, and community-based access initiatives.

Few, if any, PLWAs receive treatment through the private sector. Private insurance companies do not cover any HIV/AIDS related expenses beyond blood tests.

Government & Pharmaceuticals

The Spanish Government obtains ARVs by purchasing them directly from the pharmaceutical industry. The government is currently in negotiations with the pharmaceutical industry and is also considering generic production of treatment drugs in order to lower costs. Glaxo Smith Kline, Boeringher Ingelheim, Abbot and Roche have been approached, and possible reductions in the price of AZT are being examined.

Community Participation

Grupo de Asistencia a Seropositivos de Aragón – Gays Seropositivos de Aragón (GASPAR) has interacted with the government to improve access to treatment through lobbying and meeting with governmental officials.

International Guidelines

GASPAR was aware of the International Guidelines on HIV/AIDS and Human Rights through information received regarding the XIVth International AIDS Conference and through the ICASO website. GASPAR has not yet applied the guidelines to advocacy work, but believes they would be useful tool for accessing treatment, especially since they include plans of action.

SWITZERLAND

Right to Health & Essential Drugs List

The right to health has been recognized in the Swiss constitution since 1848 (Articles 117 & 118). Access to treatment is recognized as part of the right to health. (Article 117 par. 1) There are legal provisions at the national level that ensure access to HIV/AIDS treatment. (Krankenversicherungsgesetz, Health insurance act, 1911) HIV/AIDS treatment has been included in the government's Essential Drug List since 1994.

Access to Treatment

Treatment for HIV/AIDS is offered through the public health sector in the form of: treatment for STDs; treatment for opportunistic infections (including TB); triple therapy; protease inhibitors; NNRT; and, palliative care.

There have not been any specific programs or initiatives to benefit certain target groups in the last five years. Improvements in access to treatment and care in the last five years have included a reduction of the cost of insurance policies (depending on income) and the establishment of compulsory health insurance in 1996. The improvements have been due to the adoption of new legislation. Private insurance companies cover HIV/AIDS related expenses.

Government & Pharmaceuticals

The Swiss government obtains ARVs through purchasing them directly from the pharmaceutical industry and importing them. There have been no direct negotiations between the government and the pharmaceutical industry.

Community Participation

The Swiss AIDS Federation has interacted with the government through lobbying pharmaceutical companies.

International Guidelines

The Swiss AIDS Federation is aware of the International Guidelines but has not yet used them. The guidelines are useful in that they provide a clear demand for a global standard of fundamental rights for PLWAs. The main change in government policies in the last five years has been the 1996 compulsory health insurance. The Swiss AIDS Federation does not believe that the adoption of the International Guidelines has influenced the government in any way.

VENEZUELA

Right to Health & Essential Drugs List

The right to health, which has always been recognized in Venezuela's constitution, was clearly defined in the new constitution of 2000. The Bolivarianian Constitution of 2000 recognizes access to treatment as a component of the right to health, and HIV treatment has been included in the Essential Drugs List since 1999. National and provincial legal provisions to ensure access to HIV/AIDS treatment have been repeatedly upheld through decisions in the court system.

Access to Treatment

Estimates indicate that 60-80% of PLWAs receive treatment through the public sector. Individuals qualify for social and public insurance benefits by being employed. The treatment available through the public sector includes: treatment for STDs; treatment for opportunistic infections, including TB; triple therapy; prophylactic treatment for pregnant women; protease inhibitors; and, nutritional supplements.

In the last five years, there have been several programs to benefit specific target groups. Programs have been focused towards pregnant women, children, and employed persons. There have been improvements in access to treatment due to strong lobbying and advocacy by communities in addition to community-based access initiatives.

It is unknown how many PLWAs access treatment through the private sector. Private insurance companies cover some of the expenses related to HIV/AIDS, but the decision to do so is taken individually by insurance companies. For instance, Petroleum and Basic Industry Sector include AIDS expenses, such as hospitalization, doctor visits and blood tests. Some companies cover medication expenses up to US\$ 7,000 depending on the plan.

Government and Pharmaceuticals

The government of Venezuela obtains ARVs by purchasing them directly from pharmaceutical companies. The government is currently negotiating with the pharmaceutical industry to reduce the cost of treatment drugs and is also considering parallel importing, compulsory licensing and generic production. Negotiations have taken place with Merck, Abbott, Bristol Myers, Glaxo Smith Kline, Roche and Boehringer. As a result, Merck has reduced Crixivan by seventy percent and Stocrin by sixty-five percent.

Community Participation

Acción Ciudadana Contra el SIDA (ACCSI) has interacted with the government to increase access to treatment in Venezuela. The interaction has been in the forms of: lobbying governments; lobbying pharmaceutical companies; lawsuits; meetings with governmental authorities; and, street mobilizations.

International Guidelines

ACCSI participated in the design of the International Guidelines, and has since used them to advocate for access to treatment. Several other organizations in Venezuela have used the guidelines in preparations for legal actions, however, the guidelines have not been widely promoted. The government of Venezuela has not incorporated the guidelines into national legislation, nor have they been referred to in governmental documents. Therefore, despite ACCSI's advocacy efforts, the adoption of the International Guidelines has not influenced the government of Venezuela.

After years of denial of the epidemic, the government of Venezuela has started to recognize HIV/AIDS as a public health problem. This was a result of the Supreme Court decision (June 1999), which obligated the government to attend to all PLWAs, assign budgets, and to initiate prevention and information campaigns. In addition, the new President included AIDS in his agenda in 1999. As of March 2001, a Strategic AIDS Plan has been designed, which includes a strong human rights component. Venezuela is quickly advancing with its response to the AIDS epidemic. However, there is a need for civil society to continue awareness and lobbying efforts to ensure that policies continue to progress.

C O N C L U S I O N S

The International Guidelines on HIV/AIDS and Human Rights provides a tool to assist States in creating a positive response to the pandemic based on human rights that is effective in reducing the transmission and impact of HIV/AIDS. NGOs considered that the guidelines are a tool to advocate for improvements in the situation of HIV/AIDS. However, almost all indicated that they have not been broadly distributed to grass roots organizations. The Guidelines are an under-used resource.

NGOs have been participating in the monitoring of State compliance with international law. In the area of human rights, NGOs investigate and publicize violations of international law; thus often forcing government to comply with recognized standards. NGOs also are increasingly participating in the process of monitoring violations of human rights, in the form of reports addressed to the Commission on Human Rights. NGOs and community groups can also influence government policy through advocacy.

The increasing influence of NGOs working on HIV/AIDS, which has brought about tangible changes in public policies cannot be ignored. Many authors recognize the influence of civil society in the design and execution of public policies. The constant lobby actions performed by NGOs with different governmental officers, their critical educational and social assistance function, especially in relation to marginalized economic/social classes, their permanent participation in the media to inform about problems regarding human rights and HIV/AIDS, their street demonstrations as well as the promotion of legal ways to safeguard human rights of people living with HIV/AIDS, constitute clear examples of the NGOs' influence on public policies around the world.

This research shows that NGOs are involved in a variety of activities to improve access to HIV treatment for PLWAs. Some of these actions have been successful in providing treatment; others have drawn attention to the bigger picture of lack of equity in access to treatment or discrimination against PLWAs.

In most countries, all support guaranteed by the legislation in relation to access to HIV/AIDS treatment, is relative since the systems are complex and bureaucratic, and even though some patients receive treatment free of charge, it is not easily obtained or guaranteed on a continuous basis. This latter aspect is the most worrying because of its effect on the development of the illness. We know that HIV/AIDS treatment must be timely and continuous to be effective. It is clear after the analysis in this study, that the legal basis for protection of the right to health and its exercise and enjoyment thereof is most legitimate. But access to treatment is not only a 'legal' problem. We are witnessing a problem whose roots are historical, social, political and economical. We are facing a problem of denial of the reality.

Much work is needed to empower non-governmental organizations and the people who are most vulnerable. PLWAs need to understand the issues in order to find a way to address them. However, NGOs and advocates cannot replace

governments in terms of ensuring access to drugs. Governments should be able to ensure equitable and regular provision of HIV-related treatment. This is their obligation under the right to health. Government participation is a crucial part of combating AIDS; without active participation by governments, policies that remain oppressive and fuel the spread of AIDS will remain intact. For the most part, the guidelines have not yet been incorporated into national legislation and action.

Anti-retrovirals are available and have proven effective but are not accessible to the general population. Price is a key factor. Improving access to treatment does not depend only in lowering the price of ARVs. Weak health infrastructures play a big role in the unavailability of ARVs in some countries. Infrastructure needs to be improved/created to monitor and manage the difficult side-effects of the therapy and avoid development of resistance.

It is necessary to identify multiple strategies to gain access to treatment, which should include, among others, identifying barriers, discussing and identifying how to address those barriers, and understanding that access to treatment is a human rights issue.

RECOMMENDATIONS FOR FURTHER ACTION

The guidelines are a useful tool for education and advocacy, however, they need to be more widely promoted both to governments and to the community sector. This promotion can be enhanced by the UN system to its member States and to non-governmental organizations by the UN system of agencies and by Community Sector networks.

The profile achieved by UN Declaration of Commitment on AIDS in 2001 is an opportunity for community advocates to promote the human rights based approach and practical strategies outlined in the guidelines.

More organizations in the Community Sector need to themselves integrate a human rights based approach to their work and their advocacy. Opportunities for related training and discussion of strategies need to be made available to ensure a strong community response.



List of Countries Selected for the Research

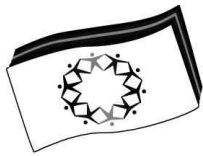
Argentina, Venezuela, Trinidad, Guatemala, Costa Rica, Canada, Japan, Australia, Thailand, Malaysia, Pakistan, Spain, Holland, Poland, Switzerland, Russia, Kenya, Senegal, Burkina Faso, South Africa, Ghana

List of Countries with NGO Participation in the Research

Venezuela, Guatemala, Costa Rica, Canada, Japan, Malaysia, Pakistan, Spain, The Netherlands, Poland, Switzerland, Kenya, Senegal, South Africa, Ghana

PARTICIPATING NGOs

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STOP AIDS NOW!	Joseph Scheich	jscheich@stopaidsnow.nl	The Netherlands
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Swiss AIDS Federation	Mr. Pierre Heusser	aids@aids.ch	Switzerland



ICASO

ICASO, the International Council of AIDS Service Organizations, works to strengthen the community-based response to HIV/AIDS, by connecting and representing NGOs throughout the world. Founded in 1991, ICASO operates from regional secretariats based on all five continents, guided by a central secretariat in Canada.

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