HIV/AIDS IN LATIN AMERICA FROM SOCIAL POINT OF VIEW
“Some will deny it, but the levels of stigma, discrimination, homophobia, fear of AIDS and transphobia are high here. That makes political action very difficult.”
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The first and foremost objective of this publication is to encourage discussion among the various actors in the public, social and international cooperation sectors on social aspects concerning the response to the HIV/AIDS epidemic. A second aim is to show that Latin America has a long experience and history of social response, which is an essential input for assessing and strengthening the response to the epidemic not only in this part of the world but also around the globe.

In this regard, the International Agency for Technical Cooperation on HIV/AIDS-CICT and the German Technical Cooperation Agency-GTZ, both located in Brasília-DF/Brazil, and the German Ministry for Economic Cooperation and Development have developed a study with the Latin American Social Sciences Institute (Facultad Latinoamericana de Ciencias Sociales – FLACSO) and the International AIDS Alliance (IAA) in twelve countries in Latin America and the Caribbean, within the framework of the Regional AIDS – Latin America Project.

This paper reports the results of analyses and studies carried out between April and August 2008. The analyses concern:

1. Las diferentes formas de interacción y participación de los gobiernos, la sociedad y la iniciativa privada en la respuesta a la epidemia de VIH/SIDA en América Latina y el Caribe, que data de más de 20 años.

2. The legislation and the judiciary as both a guarantee of human rights and components of the response to the epidemic that are widely accepted among professionals, the academy, civil society, and politicians in the region; especially the impact of legislation on AIDS prevention and treatment and its effects on civil society activities in politics and vice versa.

3. The forms of access to resources by civil society organizations, their main goals and challenges.

The preliminary results of the study analysis were reviewed and discussed at a satellite conference organized during the Global Forum on HIV/AIDS held in Mexico City in August 2008. The importance of this issue for this phase of the epidemic lies in the rich debate, the contributions of which are contained in this analysis.

With this publication we hope to contribute to a debate that goes beyond scientific, epidemiological and public health aspects pertaining to the AIDS epidemic. We hope these results stimulate a discussion on the social response to the epidemic thus contributing to a multidimensional, comprehensive understanding of the response as a whole.

Carlos Passarelli y Claudia Herlt
Some Latin American countries have been successful in getting the state to adopt legislation and policies that guarantee the right of all people to unrestricted, clear, accurate, and scientifically-based information on HIV/AIDS. Other countries have implemented anti-homophobia campaigns aimed at the general population. One of the highlights in a few countries was the adoption of laws punishing discrimination based on sexual orientation and the design and implementation of specific prevention campaigns for the lesbian, gay, bisexual, transvestite, transsexual, transgender and intersex (LGBTTTI) populations.

These achievements of the Latin American response to the HIV/AIDS pandemic, their related legislation and the guarantee of human rights are neither sufficiently visible to the international community and cooperation agencies nor addressed and discussed in depth in reports on the epidemic generated by cooperation agencies or in regional and global forums and conferences.

These reports are based almost exclusively on epidemiological indicators and do not describe the improvements in social impacts achieved in the respective countries. The situation is compounded when comparing Latin America alone to the severe impacts of the epidemic in sub-Saharan Africa or to the size of the Asian population.
Nevertheless, it is important to bear in mind that in late 2007 the Joint United Nations Program on HIV/AIDS (UNAIDS) reported 1.8 million people living with HIV in Latin America and the Caribbean. In view of these facts, the German Cooperation Agency (GTZ), the Brazilian International Center for Horizontal Technical Cooperation (CICT), the Latin American Social Sciences Institute (FLACSO), and The International HIV/AIDS Alliance have decided to conduct a survey that would enable documenting and analyzing the achievements and challenges faced by some countries in the region in three key areas: 1) public policies and legislation in defense of human rights and against discrimination; 2) the performance and contribution of civil society organizations (CSOs) in policies or legislation; and 3) access of different key populations to HIV/AIDS resources and services.

Although the epidemic affects the entire population, the study focused on key populations, as they are the not only the ones most affected by HIV but also the most discriminated against and stigmatized. In addition, these populations have an important role in the social response to the epidemic. The concept of key population used in this study refers to communities or sub-populations that are important to the dynamics of the epidemic in a certain country. This concept usually, but not always, concerns the following groups: sex workers, transgenders, gays and other men who have sex with men (MSM), people living with HIV/AIDS (PLWHA), and injecting drug users (IDUs). The term is more often used in the context of concentrated epidemic and not only offers the dimension of vulnerability to HIV but also includes behavior and work-related aspects (i.e. greater exposure to HIV) and, essentially, action” (Alliance, 2008, p. 4).

This paper presents the most relevant outcomes of the study, as well as a critical analysis of the social breakthroughs achieved by the Latin American response to HIV/AIDS and what is still pending for these achievements to be effective in all countries in the region. The purpose is to motivate governments, social organizations and the international community to take actions that help maintain the achievements, overcome the existing gaps in legislation and guarantee human rights, thus contributing to deepening and extending the benefits already made available to some. Another goal is to monitor the epidemic more closely, with social indicators that haven’t been sufficiently considered yet.

THE STUDY

As already mentioned, the investigation has been generally structured around three issues: a) public policies and legislation defending human rights and against discrimination; b) the performance and contribution of civil society organizations in policies or legislation; and c) access of different key populations to HIV/AIDS resources and services.

The study on HIV/AIDS-related legislation and public policies developed by FLACSO between March and June 2008 aims not only to identify specific policies and laws on HIV and AIDS but also to broaden the scope so as to include those that guarantee or obstruct the rights of key populations. In 8 countries (Argentina, Brazil, Colombia, Chile, El Salvador, Mexico, Peru and the Dominican Republic) priority has been given to the search for existing regulations and policies related to the four rights below:

- The right to health;
- The right to freedom from discrimination (in different areas of social life, such as the freedom to assembly, work, education, credit, the ability to legally change gender identity, etc.);
- The right to privacy (which includes confidentiality and the freedom to be tested entirely of one’s own volition); and
- The right to sex education.

The four selected key populations regarding human rights and HIV/AIDS were: people living with HIV/AIDS (PLWHA); lesbians, gays and men who have sex with other men, bisexuals, transvestites, transsexual, transgender and intersex individuals (LGBTTTI), injecting drug users (IDUs), and commercial sex workers (CSW).

Laws, regulations, national rules and public policy documents related to the four above-mentioned rights were selected and identified in each country. Interviews with government officials, representatives of civil organizations and people living with HIV were conducted. The analysis of the collected data focused on gaps and contradictions between laws, between laws and regulations, and between the legal and regulatory framework and public policies.
In Brazil, besides the data gathered by a team hired by FLACSO, information raised by the team responsible for analyzing results – which was also in charge of drafting this document – was taken into account. This has enabled assessing the conditions for applying regulations and policies, which can be very protective in their words but inapplicable to a concrete situation.

A complementary case study by FLACSO-Chile is included, which makes a diachronic comparison between people with antiretroviral treatment at two different moments in the health care system. The purpose was to support the following hypothesis: When there are rules guaranteeing access to drugs that are given out free of charge, adhesion to treatments increases and people are treated with more respect than when there is no legal support.

The other two issues of the study – performance and contribution of civil society organizations within policies or legislation and access of different key populations to HIV/AIDS resources and services – were carried out by the International HIV-AIDS Alliance and had the following specific objectives:

- Describe and analyze the achievements concerning the participation of the key populations in the multi-sectorial spaces in which public policies are designed and decisions are made, with special emphasis on describing how political impact has contributed to improving participation and political dialogue.

- Describe and analyze the achievements and challenges related to the access of the key populations to financial resources and the respective relationship with stigmatization, discrimination, lack of legal recognition and lack of domestic funding mechanisms.

A qualitative methodology relying more on perceptions than on objective data was proposed for assessing the level of political participation of the countries’ organizations as well as the extent of their access to resources. The qualitative methodology study is not intended to achieve results that are representative of all the organizations engaged in HIV-AIDS-related work in Latin America and the Caribbean, but rather to further analyze the cases of ten countries in the region namely: Argentina, Colombia, Chile, Ecuador, El Salvador, Honduras, Mexico, Nicaragua, Peru and Dominican Republic.

In this regard and considering each of the countries investigated, the survey was based on a total of 143 semi-structured telephone interviews, which involved three types of key-actors: 1) representatives of civil society organizations or networks (100); 2) representatives of governmental and intergovernmental organizations (19); and 3) representatives of funding organizations (24).

The final report was prepared based on the analysis of the surveys’ results by relating legal frameworks to both the practice and political challenges faced by civil society organizations. (References in this document relate to results reports prepared by FLACSO and The Alliance). The purpose was to describe how legal frameworks influence the actions of social organizations and vice-versa and how the actions of social organizations influence legal frameworks and, together, the two structure the social perspective of the epidemic.

1. In Mexico some interviews were carried out on a person-to-person basis by request of the interviewees.
### Table 1. Semi-structured telephone interviews

<table>
<thead>
<tr>
<th>ACTORS</th>
<th>DISTRIBUTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organization or network directors (108 interviews)</td>
<td>Collect information on the country’s progress, achievements and challenges concerning the fight against HIV/AIDS based on: profile, political participation, government openness to participation, ability to access resources, and access alternatives to available resources.</td>
</tr>
<tr>
<td>PLWHA</td>
<td>23%</td>
</tr>
<tr>
<td>MSM</td>
<td>23%</td>
</tr>
<tr>
<td>Other*</td>
<td>18%</td>
</tr>
<tr>
<td>TS</td>
<td>16%</td>
</tr>
<tr>
<td>Trans</td>
<td>11%</td>
</tr>
<tr>
<td>UDI</td>
<td>5%</td>
</tr>
<tr>
<td>Many**</td>
<td>4%</td>
</tr>
</tbody>
</table>

* Other: organizations that despite working with one or many of the key populations studied have their main focus on a different population.
** Many: basically networks that work with more than one key population.

<table>
<thead>
<tr>
<th>Representatives of governmental and intergovernmental entities (19 interviews)</th>
<th>Collect information, particularly on organization capacity for political participation and access to resources.</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Nations</td>
<td>47%</td>
</tr>
<tr>
<td>The Global Fund</td>
<td>32%</td>
</tr>
<tr>
<td>Government</td>
<td>21%</td>
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<table>
<thead>
<tr>
<th>Funding entities (24 interviews)</th>
<th>Gather information, particularly on access granted to key populations.</th>
</tr>
</thead>
<tbody>
<tr>
<td>International Organizations</td>
<td>37,5%</td>
</tr>
<tr>
<td>Religious organizations</td>
<td>20,8%</td>
</tr>
<tr>
<td>Foundations</td>
<td>20,8%</td>
</tr>
<tr>
<td>International Cooperation Agencies or Organizations</td>
<td>20,8%</td>
</tr>
</tbody>
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**THE RESEARCH AIMS AT ANSWERING THE FOLLOWING GLOBAL QUESTIONS**

- To what extent do organizations participate in decision making and in designing HIV/AIDS-related public policy, programs and legislation?
- Are there differences in the political participation of key populations?
- What changes have occurred in recent years regarding the political participation of key populations?
- To what extent do organizations have access to resources?
- Are all key populations given the same access to resources?
- What changes have occurred in recent years in key populations’ access to resources?
In this chapter we describe the human rights situation among the populations that are considered crucial to the study as well as the achievements of civil society participation in national responses to the HIV-AIDS epidemic. In this regard, we have analyzed the results and reports of specific studies on “political participation and access to resources by social organizations” conducted by the International HIV/AIDS Alliance, and the study of “HIV/AIDS-related regulatory and public policy frameworks” developed by FLACSO.

Special emphasis has been placed on the results of articulations and alliances between governments and civil society, based on their participation and on the guarantees of the rights of PLWHA and key populations - LGBTTTI, TS and IDU. The analysis focuses on two major interconnecting and mutually complementing lines: social discrimination and participation.

Historically, social movements have sought to institutionalize their demands. This is probably the reason why they have either directly or indirectly contributed to implementing state bureaucracy and might be helpful in developing both technical and political government actions. Nevertheless, government and civil society are different social actors and their interests in the outcome of partnerships are therefore also different in spite of their working together.

First of all, we will discuss various aspects of discrimination: a general aspect regarding HIV-AIDS and another one concerning key populations. According to data from FLACSO, in principle all key populations belong in the same legal field as the general population regarding the right to health. Conversely, people living with HIV in these populations have the same rights of and can suffer the same restrictions predicted by the rules for PLWHA. In addition, the fact that key populations are considered social and culturally different with respect to dominant behavior patterns and lifestyles is a contributing factor for them to remain a target of stigma and discrimination, which puts them in vulnerable situations.

It is also known that a number of social factors increase people’s vulnerability to HIV. These factors include stigma and social discrimination, which in turn motivate the creation of CSOs, especially those that uphold the rights of key populations.
Information on the history of and response to the epidemic in Latin America makes it evident that PLWHA are the victims of the heaviest AIDS-related metaphors – connected from the beginning to representations of the plague, divine punishment, a disease resulting from reckless sex and drug abuse – and catalyze key aspects of the epidemic and its necessary response. From the start, stigma has been a limiting factor for the response, especially in that it is related to social behavior and subjective aspects.

It is also expressed in acts of discrimination seen in public institutional environments and private settings and can be controlled through the guarantee and realization of rights. In general, PLWHA's right to non-discrimination is guaranteed in countries that have passed laws on AIDS – especially concerning labor, health and education rights – which seek to reduce rights violations. This includes, for example, tests without the individual's prior knowledge and consent, layoff due to HIV/AIDS, discrimination in health services, lack of access to drugs, rejection of children living with HIV by schools and many others. But despite the existence of such laws, acts of discrimination in the workplace or credit services remain a concern, especially where the law is omissive.

While PLWHA are part of the rights agenda, their expression in the field of HIV/AIDS is different from that of other key populations. This can be seen, for example, in the large difference in the number of representation posts, which shows that other key populations have less space in decision-making bodies in comparison to PLWHA, as outlined below. This can also be related to the fact that the PLWHA agenda is more specific to the HIV-AIDS issue whereas the agenda of other key populations is broader and less specialized.

Moreover, MSM and TS populations operate with the help of a strong network and have tread own path. They are sometimes allies, but generally follow their own agendas, lead different political action processes, and have different organizational dynamics and both national and international networks with no prejudice to their joint work in the struggle for rights and, particularly, against discrimination.

It is important to note that many of the advances in prevention and anti-discrimination policies are the result of gay activism, which existed before HIV/AIDS and has always been committed to the response to the epidemic.

Discrimination against LGBTTTTI populations is expressed particularly in the refusal to grant them legal personality and the lingering limitations for them to be heard and respected. The information gathered by the Alliance survey shows clear examples of this, such as the non-acceptance of their sexual identity and the refusal to give legal personality to transvestite, transsexual and transgender (TTT) organizations. These situations not only affect rights, but also limit access to resources and services.

The right to freedom from discrimination based on sexual orientation is not provided for in the constitutions of Latin American countries. All there is are some acts that recognize sexual orientation, but have no coercive force. Research conducted by FLACSO shows that there is no recognition of gay families for social security purposes and that discrimination based on sexual orientation needs to be discussed with health care. These are examples of the limitations LGBTTTTI populations face to express their citizenship and the social settings that discriminate against them. Acts of homophobia are another clear statement against this population that may result in physical assault and even murder.

Response to discrimination in the studied countries was found to be very diverse. In some cases, specific measures have been created by actions that were not limited to the National AIDS Program and include mechanisms for receiving complaints and attempts to fight discrimination. In other cases, national strategic programs that are closer to national AIDS policies have been developed. Finally, there are countries where no action at all has been taken. The examples of Mexico and Brazil are noteworthy. Mexico has programs covering health, education, and work, in addition to mass media campaigns aimed at the LGBTTTTI population. In both Brazil and Mexico, national AIDS policies include the elimination of stigma and discrimination against PLWHA and key populations. In Brazil, there is a program designed specifically for LGBTTTTI called “Brazil without Homophobia.”
With regard to sex workers, the most important aspect related to discrimination is the absence of the right to physical integrity. In some countries, professional sex is a crime. One of the examples presented by FLACSO mentions that the Salvadoran Penal Code establishes a penalty of 4 to 8 years in prison for demanding or soliciting “prostitution services”. Because of the legal penalties, sex workers are continuously abused, sometimes in the name of morality and decency often used to criminalize LGBTTTI as well as sex workers. There are also cases of corruption, in which the police harass sex workers for bribes. Another case of discrimination against these people is the requirement of identification cards (in Colombia and Chile) that, besides being required for health care are a tool for monitoring sex workers – a clear violation of their right to privacy. In the case of Chile, this control is under the responsibility of the civilian police. In general, health services tend to control professional sex and rarely recognize the rights of sex workers.

An important exception to this rule is found in Peru, where the police are provided with a human rights manual stating that abuse and discrimination affect human dignity (FLACSO, 2008, p. 79).

Brazil has implemented an Integrated Program to Fight the Feminization of the AIDS epidemic and STDs, which includes actions aimed at sex workers. The brazilian program has also been working in coordination with the National Peruvian AIDS Program, the Sex Worker Network for HIV/AIDS in Latin America and the Caribbean (REDTRASEX), the Latin American and Caribbean Trans Network (RedLac-Trans), and the organization of the Regional Summit on Sex Work and HIV/AIDS in Latin America and the Caribbean (Lima, February 2007). The summit was sponsored by the Horizontal Technical Cooperation Group (HTCG) based on the commitments of the Special Session of the UN General Assembly on HIV/AIDS (June 25-27, 2001) concerning universal access to comprehensive prevention, treatment and care programs, and responding to the demand of TS organizations for more thorough discussions on the relation between sex work and HIV infection.

It is also important to note that some countries have been debating bills against discrimination or concerning the decriminalization of sex work, as are the cases of Brazil, Chile, Ecuador, Mexico and Peru. In addition, some CSOs have been acting to reduce discrimination against sex workers, mostly with international support. In Peru, the projects of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) have contributed with actions to defend these populations (Alliance, 2008, p. 22).

There is clear evidence that injecting drug users are in worse situation both in terms of discrimination and political visibility. A prime factor for this is that some Latin American countries still relate drug abuse to mental health problems. In most cases, discrimination against IDUs is due to the criminalization of drug use. This situation led to difficulties in locating organized IDU groups that could participate in the research. In general, injecting drug use is illegal in Latin American countries. In Colombia, there is a ruling favorable to differentiating dealing, transportation and sale from consumption. In Brazil, the law envisages the possibility that IDUs receive treatment without being criminally charged. In general, existing actions are associated with HIV/AIDS prevention.

In short, according to the survey the main legal gaps and contradictions lie on the right to non-discrimination, which is also a crosscutting element in the entire regulatory system. Stigma, discrimination and lack of legal recognition are also associated with limited participation of key populations in public policies, prevention programs and access to funds.
The concept of activism within the legal framework and electoral representative democracies usually takes the form of lobbying - writing letters, holding meetings or making statements to the press and political leaders in favor of a certain cause – in order to promote or simply follow certain behaviors that are believed to contribute to the cause (...). An activist is a person who does that openly (...).” (Alliance, 2008, p. 3).

Obviously, the spaces of everyday life and political debates are shared by activists\(^2\), but what are the implications, if any, of shared trajectories in participation? The following analysis tries to answer that question.

Throughout the history of the epidemic, participation of PLWHA and key populations in decision-making bodies has been the result of pressure from organized groups, HIV/AIDS-related international policies, and forums provided by the government.

Thus, several countries have created national HIV/AIDS committees, probably as a first formal articulation space for social actors involved in the response to the epidemic. In most countries, the participation of CSOs in different decision-making arenas has been encouraged by international organizations such as the UN and, more recently, the Global Fund (GF) and key populations. Virtually no country has a relationship between governments and civil society in areas other than HIV/AIDS. In this regard, it is evident that the partnership between government and civil society is important and has contributed much to joint actions aimed at responding to the epidemic. However, actors sometimes miss their points of intersection, and this could hamper the debate on the gaps and limits of existing policies and responses.

Based on the result of the Alliance study, it is possible to say that in some countries dialogue and policy-making serve but the interest of international commitments made by the government, as in the cases of Colombia and Nicaragua. Ecuador is reported not to have any governmental space where CSOs can operate, whereas Honduras and Chile do not contemplate their participation at all. In the Dominican Republic, Colombia and Mexico, CSO participation is either irregular or has no political weight, in spite of the high number of representatives in Colombia and Mexico, which leads to the conclusion that there are formal spaces in these countries but there is no sufficient contribution to joint decision-making. On the other hand, there are countries with more participatory policies, including governmental ones, like Peru, Chile, Mexico and Brazil. In Peru, for example, there is a governmental initiative called “participatory budget”, in which organizations can criticize and propose changes to public budgets. This is different in other countries, where participation is tied to government calls to provide resources to organizations and using their experiences. Brazil, however, conducts participatory budgeting in some cities, where local problems are generally discussed with no specific focus on HIV/AIDS-related issues. In addition to this, there are calls for HIV/AIDS projects, and spaces are promoted for participation in debates on specific matters related to the key populations.

Key populations currently participate in different instances, like national decision-making arenas (multisectoral AIDS councils and/or specific government bodies).

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\(^2\) “The concept of activism within the legal framework and electoral representative democracies usually takes the form of lobbying - writing letters, holding meetings or making statements to the press and political leaders in favor of a certain cause – in order to promote or simply follow certain behaviors that are believed to contribute to the cause (...). An activist is a person who does that openly (...).” (Alliance, 2008, p. 3).
The people interviewed by the Alliance say that the achievements in the decision arenas are positive. Some of the people interviewed stated it was the first time they met such a strong group, one that could knock at the door of authorities (Alliance, 2008, p. 21). Interviewees have also highlighted some challenges:

- Increase the number of representatives in these spaces, since they are the majority and, in some cases, UN agencies and the Government “are one and the same”.
- Switch from the presence in debate arenas to the presence in documents.
- Set up real and effective AIDS councils and multisectoral decision-making mechanisms.
- Have a more active role as civil society, i.e. one that is not limited to the execution of projects or the submission of diagnosis but that also includes proposing solutions.
- Respond in a coordinated manner as civil society since sometimes it appears that everyone tries to serve their own interests (Alliance, 2008, pp.18-9).

The results of the survey suggest that participation has sometimes become a state policy or a particular brand of an administration that is respected and promoted. In some countries, civil society participation is institutionalized by concrete guidelines and regulations – as in Brazil, Chile, Peru and Mexico (Alliance, 2008, p.21).

Despite the differences between countries –such as the number and types of organizations representing key populations and their degree of importance and validity (Alliance, 2008, p.16) – one can infer that the profile of the epidemic and the political pressure exercised by PLWHA have changed, increasing the degree of articulation and political strength of their networks. This is a result of their inevitable connection with health care, despite the fact that the mechanisms that legitimate the participation of other key populations in HIV/AIDS-related decision-making are still not very clearly outlined. In fact, these key populations, whose relationship with health care is different from that of PLWHA, have occupied other spaces. In Brazil, for example, they have gradually occupied new areas in different sectors such as human rights, justice and culture, expanding and changing partnerships in specific HIV/AIDS instances. It is also necessary to consider that the priorities of the ministries and dialogue with civil society have been combined by multisectoral policies, creating a new configuration.
Table 2: Participation of PLWHA and key-population in decision-making forums

<table>
<thead>
<tr>
<th>Country</th>
<th>Participation in decision-making forums in the country</th>
<th>Key-Populations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>National Committees</td>
<td>MCP</td>
</tr>
</tbody>
</table>
| **Argentina**   | PLWHA Technical Advisory Committee – AIDS and STDs* 1 CSO | 2 OSC | 2 PLWHA | 1 PLWHA is the same at the three levels  
* UNAIDS conducts 2 consulting meetings a year with 7 networks including 1 TS and 1 Trans. |
| **Brasil**      | CNAIDS ** 5 OSC CAMS *** | Under development | 2 OSC | CNAIDS: 4 PLWHA (3 alternates), 3 MSM (1 alternate) and 1 TS  
CAMS: 1 in each population (PLWHA, TS, MSM, TTT, and IDU)  
UNAIDS: 1 PLWHA |
| **Chile**       | No participation | Country Committee | 2 OSC | The same 2 OSC | 1 PLWHA, the same at both levels |
| **Colombia**    | CONASIDA **** 9 OSC, siendo 5 the same as MCP | 7 OSC | No participation | 3 PLWHA, 2 being the same at both levels |
| **Ecuador**     | There is no such forum | Coord. ONG/Sida Guayas - 8 OSC | No participation | 2 PLWHA 1 MSM, 1 LGBT y 1 TS |
| **El Salvador** | CONASIDA 1 OSC | 10 OSC | Under development | 3 PLWHA, 1 being the same in CONASIDA |
| **Honduras**    | No participation | 2 OSC | No participation | 1 MSM (Gay), 1 TS (alternate) and 1 TTT (alternate) |
| **México**      | CONASIDA 6 OSC | No MCP | 2 OSC | CONASIDA: 4 PLWHA  
UNAIDS: 1 PLWHA and 1 HSH |
| **Nicaragua**   | CONASIDA 1 OSC | 8 OSC | No participation | 4 PLWHA, 1 being the same in CONASIDA |
| **Perú**        | Strategic Cross-Sectoral Plan (CONAMUSA participates) 7 CSOS | Coord. Nacional Multisectorial en Salud (CONAMUSA) Country Committee 7 OSC | No participation | 2 PLWHA |
| **República Dominicana** | No participation | Presided by the Main Beneficiaries of the Global Fund 6 OSC | No participation | 3 PLWHA |

**TOTAL** | 30 PLWHA – 7 HSH – 1 LGBT – 2 TTT – 4 TS – 1 UDI

Source: Alliance/INSAD

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* PNLRH – Sida and ETS: National Program to Combat Human Retrovirus, AIDS and STDs.  
** CNAIDS: National AIDS Commission. There are 41 members and their alternates. As for CSOs, there is still an NGO Forum / AIDS and 3 NGOs / AIDS (1 alternate).  
*** CAMS: Joint Commission and Social Movements. They are present in addition to PLWHA and key populations. 10 representatives of each NGO Forum / AIDS and 10 representatives of the 4 movements. Black and indigenous people, women, and students. Institutional representatives are not the same in CNAIDS.  
In other cases, participation in managing programs interferes with the priorities of CSOs and overloads their human resources. Anyway, promoting exchange and discussion among stakeholders in the design, implementation and evaluation of policies continues and has yielded successful cases. In Brazil, dividing CSO representatives into committees, commissions and work groups is part of the democratic process. A National Conference of the Movement against HIV/AIDS is held every two years, generating political debate on their participation in the government structure. The meeting holds elections to inform the government and other agencies who the representatives of this movement are.

In other countries like Argentina and Chile, where the national authority is theoretically unisectoral, stakeholders are consulted at a certain point. It is also possible to notice in the FLACSO study that in countries where authorities are multisectoral, at least the Ministries of Health and Education, representatives of CSOs, representatives of PLWHA and international cooperation agencies are involved. The armed forces participate in the Dominican Republic; and the police, in Chile. In Brazil, the Dominican Republic, El Salvador and Colombia the private sector (including health insurance entities) and religious groups are included as well. Brazil has well-known health councils that discuss and decide on public health policy at the three government levels and which count on the participation of civil society representatives involved in HIV/AIDS-related matters.

Another noteworthy example is the action of the Parliamentary Front to Fight AIDS, which gathers representatives from different political parties, and the Corporate Council for National HIV/AIDS (large companies with prevention activities).

Other important factors differentiating the political participation of organizations include:

1) Membership in a particular social group;

2) Participation at national or local level. Based on the interviews, 62% of the organizations located in a country’s capital belong to a national network, while 69% of them have legal status. In the case of organizations not based in capital cities, only 51% are in a national network and 43% have legal personality;

3) Belonging to a network is considered a key factor to ensure participation in decision-making spaces (80% of CSOs surveyed are connected to networks); and

4) The profile of organizations, considering the following characteristics: “a) having legal personality; b) age, background, experience and degree of group organization; c) technical capabilities of its members; and d) the degree of access to resources and services.” (Alliance, 2008, p. 24). Few organizations get involved in decision-making arenas unless they fit this profile.

From another point of view, it is important to understand the quality of representation: if the people occupying seats were in fact representing their respective organizations, they should be included in the public debate. For representation to be effective, all organizations must reflect on its meaning and on the process of choosing their representatives, who must commit to their organizations. The fact is that representatives sometimes do not represent; there is no clear process to select and invite representatives since this is not up to the organizations alone.

Table 3 shows that both the government and civil society are present in all partnerships that are established to deal with HIV/AIDS. It is important to note that even if the current challenge in the international arena is to develop preventive and anti-discrimination strategies, participation of key populations in decision-making is a condition that may affect policies.
CSO PARTICIPATION IN NATIONAL PLANS AND PROGRAMS

Based on Alliance data, it is possible to describe not only participation but also the involvement of CSOs in designing national plans and programs to fight HIV/AIDS. Interviewees’ opinions on the matter were controversial. Some argued that civil society was essential to develop plans and laws, whereas others considered that while CSOs attended planning activities, their participation was minimal and little effective. This has been literally said: “(organizations) are many times asked to give their opinion on something that has already been decided on” (interview with Alliance, 2008, p. 23).

There is also participation in developing other national documents, such as proposals to the GF and reports to UNGASS. Except for Honduras, all countries had at least one organization that reported such participation, which is a step toward a greater political involvement of organizations working with key populations. This points to the fact that the current scenario of the HIV/AIDS epidemic is more related to political logic than to the pressures of certain death and medical uncertainties.

In addition to the formal approach to participation, we can talk about things that are experienced but seldom mentioned in the daily discourse. At this point, two questions arise: “What does it mean to participate in making government plans?” and “Does the number of representatives in committees or commissions guarantee civil society participation, even when people have a say?”

Table 3. Institutions and groups participating in HIV/AIDS policies, by country

<table>
<thead>
<tr>
<th>México</th>
<th>Chile</th>
<th>Perú</th>
<th>Argentina</th>
<th>El Salvador</th>
<th>Dominican Republic</th>
<th>Colombia</th>
<th>Brasil</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
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<tr>
<td>Civil society</td>
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<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
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<tr>
<td>Religious organizations</td>
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<tr>
<td>Private entities</td>
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<tr>
<td>Health care</td>
<td>⬠</td>
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<tr>
<td>Armed forces</td>
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<td>⬠</td>
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</tr>
<tr>
<td>PLWHA</td>
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<tr>
<td>LGBTTI</td>
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<tr>
<td>Sex workers</td>
<td>⬠</td>
<td>⬠</td>
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<td>⬠</td>
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<tr>
<td>UDI</td>
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<td>⬠</td>
<td>⬠</td>
</tr>
<tr>
<td>Others</td>
<td>⬠</td>
<td>⬠</td>
<td>⬠</td>
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<td>⬠</td>
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</tr>
</tbody>
</table>

The study of the International Alliance against HIV/AIDS highlights the following positive aspects of the political participation of key population organizations.

1. The existence of multisectoral areas. The existence of strong social movements and the political weight organizations have in some countries are a key factor in opening up new spaces. This is potentialized by progressive policies from mechanisms such as the GF and policies driven by civil society and progressive governments.

2. Increased and improved participation of civil society in different decision-making arenas at national, regional and local levels. Although this is in many cases real, it is still necessary to further the understanding and analysis regarding the quality of participation.

3. The active role of organizations in the collective development of the response to HIV-AIDS. In some cases there are limited or no economic resources to mainstream them into the debate.

4. Organization involvement in designing national plans and programs to fight HIV/AIDS and in passing or amending relevant legislation.

5. Changes in government-civil society relations. From confrontation to consensus, continuous dialogue between government and organized civil society has been made possible – something that was considered impossible a few years ago. There are, however, disagreements that are perceived as demobilization.

6. Openings for vulnerable population representation in high-level decision-making forums. PLWHA is the most widely represented group among those affected by the epidemic. Nevertheless, there are countries where it’s been possible to incorporate vulnerable populations with different degrees of representation.

7. An achievement that was not sought, but earned, is the positioning of the organizations in the response to HIV/AIDS. Their model is considered the one to be followed because of the results of their political work.
This chapter discusses the legal frameworks related to HIV/AIDS in order to describe legal achievements in the studied countries. The study analyzed legal responses to HIV/AIDS matters, their trajectories and impacts on public policies and on the lives of key populations.

Basic information was obtained from two studies: one focusing on HIV/AIDS-related regulatory frameworks and public policies developed by FLACSO and another on social organizations’ political participation and access to resources in ten Latin American countries conducted by the International AIDS Alliance. Analysis included achievements and situations of legal void – where the strengths and weaknesses of legal systems have been highlighted – and how international organizations can help overcome the problem. It also focused on legal frameworks, prioritizing national legislation and rules and, whenever necessary, referring to regional laws according to their relevance to the subject.

Contextualizing the historical process of the response to the epidemic in the region enables observing that while the emergence of the HIV/AIDS epidemic has brought much pain to people who were and are affected and living with the virus, it has also triggered a civil society movement to demand an official response from the state.

As many people were facing the epidemic, social movements began to organize to call the attention of public health services by including the disease in the list of those to be treated by the state. As the FLACSO study points out, the primary objective of all actions in the 1980s was to provide health care to people living with the disease. In this sense, the main objective was to regain the right to health. The most significant effects were seen in the extension of rights and internal changes that allowed the right to health to evolve from one without any perspective to the right to full health care. In those years, scientific breakthroughs such as retroviral drugs brought better quality of life to PLWHA. After this critical phase and as the epidemic advanced, a number of actions mobilized civil society and international cooperation, leading to the first struggles for the rights of the PLWHA.

Currently, the response tends towards the defense of and respect for human rights, combined with efforts to achieve improved access to services.
Achieving Rights with Court Rulings

In many countries, key population rights were initially granted by rulings from both national and international courts. People who felt their rights had been violated – regardless of the angle – went to court and most times were given favorable rules which, in turn, forced the State to take specific actions that gradually became public policies. This is evident in legal framework reports from Colombia, El Salvador, Peru, the Dominican Republic and Chile among others.

Mention should be made of the cases highlighted by the survey to see how they have influenced or determined the State’s official position on public policies, whether or not through international organizations. There are cases where international human rights agencies were called in to mediate a situation of rights violation and helped create a public policy. Some examples of this are described below:

- An iconic example comes from El Salvador, where a case the Constitutional Court was taking too long to rule on was referred to the Inter American Human Rights Commission. The IAHRC recommended that the country should commit to providing antiretroviral drugs to people who had requested them from the state. The result of the recommendation was the Constitutional Court recognition of the right to treatment for people who had asked for it. Subsequently, the Salvadoran State passed an act to prevent and control HIV-induced infection.

- Another important case is that of Peru, where a group of people living with HIV legally demanded access to medical care and treatment. As there was no reply, they sought the intervention of the IAHRC to guarantee their right, thereby achieving precautionary measures. It would be realistic to say that this case led to the passing of the 2004 Universal Access Act in Peru.

- In the Dominican Republic, PLWHA also filed a suit against the state. The suit resulted in a recommendation from the IAHRC to the Dominican State to provide drugs free of charge, which was a decisive factor to passing the 2000 act.

Thus, PLWHA – as well as other populations in more vulnerable positions like sex workers and LGBTTI – struggle for the states to recognize them in both their public policies and legislation. The situation has come to one where two important sides oppose one another: on the one hand, collective sanitary control and “protection” of society based on the false idea of protection from infection through isolation; and on the other the rights of policy beneficiaries. It is in this social context – marked by the stigmatization of the disease and by people living with HIV, a situation that has persisted since the early stages of the epidemic – that social movements have operated.

The study also suggests that access to antiretroviral drugs has changed the perception of fear of death due to HIV/AIDS but not the fear of stigmatization, rejection and discrimination, which persists in both PLWHA and other key populations. This is a factor that increases vulnerability.

In the process of defending the rights of PLWHA and other key populations, countries have provided their own answers to urgent requirements and demands according to their own legal contexts.
In Argentina, people with HIV/AIDS sued the State for continuous and permanent access to all medications needed for full treatment and rehabilitation in all health services in the country. They were successful in that the Supreme Court ruled in their favor on June 1st, 2000.

A similar process took place in Brazil. After several successful suits against the state, PLWHA were granted access to antiretroviral drugs by an act passed by the Federal Legislature.

These cases show how legal action taken by civil society have succeeded in achieving laws that either directly or indirectly support public health policies in Latin American countries.

The search for the guarantee of rights through judicial means, boosted by civil society movements is not restricted to HIV/AIDS-related issues, as shown by a case reported in Colombia involving sex education. Colombia created a National Sex Education Project after the Constitutional Court determined the implementation of a sex education policy. In the studied countries it is evident that in most cases laws were passed to guarantee PLWHA rights following legal demands by civil society. According to the information gathered by the Alliance, 70% of the associations interviewed focused their activities on advocacy and the results would not be as relevant if it hadn’t been for the activism of these associations. This information is confirmed by the FLACSO study.

While the use of trials and international treaty mechanisms can be considered a progress, it is unjustifiable that citizens have to resort to the Judiciary or to an international organization to secure a right that the Constitution itself grants them. It is also unfortunate that countries will only debate the rights of a specific segment of their population when pressured by international organizations.

Whereas legal achievements concerning rights are noteworthy, so is the fact that after thirty years of epidemic some countries still have no laws regarding PLWHA rights. This is the case of Mexico and Brazil.

In Brazil, despite a series of achievements in assistance to PLWHA, there are no federal laws guaranteeing their rights. Laws to protect PLWHA from discrimination are included in state-level legislation, as in the cases of the Brazilian states of São Paulo, Paraná and Espírito Santo.
In Mexico there is no AIDS-related law. It is the Mexican Official Rules, whose validity is restricted to the Ministry that created them, that regulate the matter. For example, rules against discrimination in health services do not apply to discrimination at the workplace.

This study leads to the conclusion that the response to the HIV/AIDS epidemic in Latin America has evident connections with civil society actions and the impacts of legislative decisions, which have motivated the making of laws that guarantee general health and, consequently, public policy. This is shown by the chart below.

Although the process represented by the chart is not exclusive to rights achieved by PLWHA, this is a common path in the studied countries.

The Alliance study also shows that some governments have been more open than others to the required changes in public policy in order to recognize PLWHA rights, which has helped the struggle of associations.

From another point of view, in some cases it is possible to say that a particular law or public policy has been implemented thanks to the intervention of an international organization, and not because of social demands. It is therefore important to point out that there are mechanisms that have been used to guarantee the human rights of the studied groups: legal mechanisms, both at national and international courts; quasi-judicial mechanisms, through agreements with agencies such as public defense entities, ombudsmen or human rights commissions; and finally, the political human rights defense mechanisms, which involve freedom of speech and rights defense demonstrations.

Therefore, the lack of laws does not necessarily mean the absence of mechanisms to make the state recognize rights, what can be clearly seen when associations succeed in achieving favorable public health policies. In this regard, the conclusion is that some of the changes that have taken place so far can be attributed to PLWHA social movements, combined in some cases with legitimate pressure from international human rights organizations.

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**Figure 1. The process of achieving laws/policies judicially**

1. Absence of laws and/or public policies.
3. Court Rulings are complied with. States take action.
4. Laws to guarantee rights are made.
5. Public policies are designed or strengthened.
6. Favorable Court Rulings. Determinations against the State.
The effects obtained from the publication of a law that guarantees human rights can be illustrated by two key examples: in the Chilean case investigated by FLACSO-Chile (see annex) and in Brazilian statistics.

The case study shows the difference in access to and respect for the rights of PLWHA, before and after access to antiretroviral drugs and the publication of the Law on AIDS. It is possible to see the benefits brought by the law. Before universal access and the AIDS law in Chile, PLWHA had to cope with many problems to care for their own health. Antiretroviral drugs were not made available to everybody, were too expensive or – as a person interviewed by FLACSO said – had to be obtained from friends living abroad. This led to the existence of a black market that encouraged corruption and hindered adherence to treatment, since many people sold the drugs to get more money. The sheer lack of legal protection was fertile ground for the stigma imposed on PLWHA.

The effect of legislation on the quality of life of PLWHA may also be statistically analyzed. Data on Brazil, for example, show that since the universal access law (1996), deaths due to HIV have been decreasing year after year – a clear example of how laws can benefit people. Lives of PLWHA have changed radically after the universal access law, since it has opened up opportunities for people living with HIV to seek new human rights issues once the basics in terms of drugs is guaranteed.

An analysis of the results of both surveys leads us to conclude that the legal advances achieved are related more to the rights of PLWHA than to those of other key populations under study. It also shows that whereas PLWHA have clearer objectives in most countries, other key populations are still in the process of clarifying their identities, which would allow them to occupy spaces in public policies in a way that best fit their own objectives and interests.

The absence of characterized identity and objectives also causes some populations in some countries to be represented by others (for example, trans by MSM), a situation that makes it difficult for these segments to be heard in their own right. In most countries, while PLWHA associations are mainstreamed into public policy making, organizations of other key populations are still struggling for essential rights like the right to legally exist (TS and IDUs).

Hypothetically, maybe this is a reason why this study did not gather sufficient information about the existence of public policies to ensure the rights of these key populations.

Another situation in which there is conflict between key populations and the law is when they try to legitimate their associations or organizations. Reports from the countries studied show the state has denied recognition of legal personality to some associations. The Argentinean report tells the case of the Argentinean Homosexual Community created in 1984, which was denied the right to have legal personality even after following all the required legal steps. This decision was confirmed by the Supreme Court and reversed only by political means through executive intervention. Not having legal personality means, in many cases, having no access to funding – national or international – for projects. Moreover, it is an indirect form of discrimination since it blocks access to public policies.

ACHIEVEMENTS IN THE DEFENSE OF RIGHTS

It is known that the struggle to defend the rights of key populations is not over yet. There have been, however, several noteworthy achievements in recent decades, which can be motivating examples to people in countries where those rights are not yet fully guaranteed, and perhaps also to save or reduce suffering and waste of time and energy in the process (see Table 4).

The constitutions of many of the countries in the study grant freedom from discrimination, but this does not mean this right is respected by the State itself. In some countries, anti-discrimination laws were passed at the time HIV emerged and do not always provide mechanisms to make their respective rights effective. Once again, laws were put in place as a program or a prediction of the rights that must be achieved and respected. In this context, the intervention of the judiciary system is once again necessary to enforce the realization of the rights provided for in the law. Passing laws does not necessarily mean that the rights of beneficiaries have been respected by the State or by others, but rather that it is still a specific regulatory framework that does not always guarantee all the rights.
On the other hand, the emergence of AIDS and its subsequent evolution has made it possible for other populations, which until then had no official space in society, to organize in order to have their rights recognized. This is the case of populations like LGBTITI, TS and IDUs, who have also mobilized to have the State recognize them as subjects of rights. The struggle of these organizations – whether through the legislative or the judiciary branch or public policies – has resulted in many changes such as laws recognizing their rights.

### a) The right to health

The law providing for universal access has been implemented in several countries, but universal access does not always come without obstacles. For example, in Colombia the law determines that in order to have access to antiretroviral drugs people must make a series of monthly contributions to the health system for a minimum period of time. This condition must be fulfilled, and access to treatment may be cut off if payments fail to be made. This is a case of financial discrimination, since the law is indirectly discriminating against those who do not make the payments.

### b) Right to privacy

In some countries reports point out some situations in which the right to privacy has been violated. In El Salvador and the Dominican Republic, for instance, people have the obligation of communicating their sexual contacts and serological situation. In Peru, PLWHA are assigned a Personal Support Agent, which means having a person who necessarily knows their HIV status and supports them to maintain treatment in the long run. Since this is an obligation, this situation violates the right of PLWHA to decide who is to know about their health status. Although this obligation may look like a positive thing at first, it is not only an invasion of privacy but also a disregard to the ability of PLWHA to make their own decisions, as if they were incapable of adhering to treatment without someone else’s help. This case once again shows the tension between the interests of the State, which seeks to be more effective in implementing its public policy of adherence to treatment, and an individual’s right to choose to let other people know about his or her health condition.

Another example has been reported in Chile, where the armed forces require HIV tests for admission, once again not respecting people’s right to privacy. In Mexico, PLWHA who enlist in the military are required by law to be categorized as “unfit”, what configures not only a violation of privacy rights but also employment discrimination.

### c) Right to freedom from discrimination

The law regulating the adoption of children in El Salvador is discriminatory as it requires foster parents to be or have been married, excluding the process those to whom marriage is not permitted by law (lesbians, gays and trans, for example).

The Dominican legal system, for example, discriminates against sex workers because their profession is not regulated by law, by excluding them from the legal system and denying them the right of access to social security. The same situation occurs in Mexico, where besides being discriminated against, sex workers are also subject to arrest by the police.

The most common conflict – observed throughout all the countries in the study except Brazil and El Salvador – has to do with immigration. Almost every country requires foreign nationals who want to live in their territory not to have infectious or contagious diseases; otherwise they will have their entry or stay in the country denied. This means that the right to non-discrimination does not exist, since the State itself determines the refusal of entry or stay in the country based on an individual’s health condition. Conflicting rules are issued by the same entity, prohibiting discrimination on the one hand and on the other confirming and authorizing it. These are cases of both migratory discrimination and violation of privacy.

Another important point is how the law deals with workplace-related rights. Managers and supervisors can legally determine what tests their employees must be submitted to, even where these are legally prohibited. A particular situation has been reported in the Dominican Republic, where in spite of the law protecting the privacy of PLWHA in regard to their professional relations, clinics commonly communicate test results to supervisors without the workers’ previous consent or knowledge – a clear violation of their legal rights.
<table>
<thead>
<tr>
<th>Country</th>
<th>Law 1</th>
<th>Law 2</th>
<th>Law 3</th>
<th>Law 4</th>
<th>Law 5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Brazil</strong></td>
<td>Law 9313</td>
<td>Ensuring universal access to antiretrovirals</td>
<td>Law 9656</td>
<td>Determines that private health system cover costs for treatment of HIV-AIDS.</td>
<td>Implementation of national harm reduction policy.</td>
</tr>
<tr>
<td><strong>Chile</strong></td>
<td>Law 19,779</td>
<td>AIDS Law</td>
<td>Law 19,628</td>
<td>Regulates the protection of privacy of individuals.</td>
<td>Creation of the Department of Non-Discrimination and Intercultural Division of Social Organizations.</td>
</tr>
<tr>
<td><strong>Colombia</strong></td>
<td>Law 972</td>
<td>AIDS Law</td>
<td>Prohibits mandatory HIV testing for admission into sports, social or rehabilitation centers.</td>
<td>Acceptance of same-sex couples into the health system.</td>
<td>Judicial recognition that prostitution and homosexuality are valid options in the social rule of law and cannot be discriminated against.</td>
</tr>
<tr>
<td><strong>El Salvador</strong></td>
<td>Legislative Decree No 588</td>
<td>Use of mechanisms and rights provided for in international agreements to guarantee the right to health.</td>
<td></td>
<td>Bans the requirement of HIV testing for entering the country.</td>
<td></td>
</tr>
<tr>
<td><strong>México</strong></td>
<td>NOM-010-SSA2 1993 (Official Mexican Standards)</td>
<td>Constitutional reform of 14 August 2001 - Prohibition of discrimination.</td>
<td>Using the principle of interpretive preference so as to privilege the interpretation favoring fundamental rights.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Peru</strong></td>
<td>Law 26,626</td>
<td>National Plan to Combat AIDS</td>
<td>Law 28,243</td>
<td>Guarantees universal access to antiretrovirals.</td>
<td>Possibility of constitutional appeal to guarantee the right to freedom in cases of discrimination by reason of sexual orientation.</td>
</tr>
<tr>
<td><strong>Dominican Republic</strong></td>
<td>AIDS Law No 55-93</td>
<td>Prohibition of compulsory testing on persons deprived of liberty.</td>
<td>Use of rights and mechanisms under International Covenants to ensure the right to health.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**d) The right to sexual education**

Information from the study suggests that sex education is a very important issue which, in almost all countries surveyed has not yet been sufficiently established as a right. In some countries there is reference to a sex education plan whose implementation has failed for some reason. The main reasons for sex education plans failure to being implemented are related to pressure from conservative groups and the Catholic Church. In Chile, the curricula prescribed by the Ministry of Health and/or Education are not compulsory for private schools. In the Dominican Republic, basic education policy is grounded on an agreement between the Ministry of Education and the Catholic Church. In El Salvador, the religious sector is part of the country’s GF Coordinating Committee. In Mexico, it a right-wing organization that opposes the use of condoms has been reported as the source of information to develop sex education curricula. The Catholic Church has been reported to hinder condom distribution programs in Argentina.

**e) Public policies specific to key populations**

Regarding public policies, the most common gap in all studied countries has to do with sex workers, LGTTTI and injecting drug users. The population of injecting drug users is virtually nonexistent when it comes to public policies. These, when mentioned, are usually related to drug offenses under the penal code. This is a great paradox: IDUs are involved in public policies and, at the same time, punished by them. With rare exceptions -like in the case of Brazil, which formalized a harm reduction policy for IDUs- it was rare to find information in countries that referred to a specific policy for this key population.

These situations are the result of the way a country’s legislative system is set up. Mexico defines its actions regarding HIV/AIDS primarily in two Mexican Official Rules issued by the National Advisory Committee for the Regulation of Disease Control and Prevention. On the one hand, because they were issued by an executive entity, these rules have the advantage of being processed at a faster pace, as they follow a process that is independent of the slow legislative process that a federal law would require. On the other hand, however, the fact that these rules are issued by an entity which most of the times is run by the government’s most trusted officials jeopardizes their continuity and force, since they rely on the permanence in office of these people, who are subject to the instability of and changes in public politics.

It is important to say that a legislative process that favors the establishment of public policies by running a process independently from the regular law-making procedures is not always conducive to human rights. In the case of Mexico, it’s valid to point out the need for regulation (NOM) preventing PLWHA from being discriminated against at work, since the present rule is effective only as far as health services are concerned.

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**Coverage of the Rights of Key Populations**

The chart shows that the rights to health, freedom from discrimination, and privacy are generally guaranteed to the population at large. However, an analysis of the public policies that enforce these rights shows that their coverage is larger for the population in general than for PLWHA, LGTTTI, TS and IDUs. The same happens when analyzing legal rights, which are more effective for the general population than for key populations. In other words, stocks that are on the tip of the inverted pyramid are those with less guaranteed rights regarding health, non-discrimination and privacy, and are also those who get less coverage from public policies.

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**Figure 2. Pyramid for the analysis of regulatory frameworks**

- Population in general
- PLWHA
- LGTTTI
- Sex workers
- IDUs

It is important to say that a legislative process that favors the establishment of public policies by running a process independently from the regular law-making procedures is not always conducive to human rights. In the case of Mexico, it’s valid to point out the need for regulation (NOM) preventing PLWHA from being discriminated against at work, since the present rule is effective only as far as health services are concerned.
INCONSISTENCIES BETWEEN REALITY, COURT RULINGS, THE LEGISLATION AND PUBLIC POLICIES

According to the study, there is little harmony among government branches - the Executive, the Legislative and the Judiciary - regarding the rights of PLWHA and other key populations. Moreover, the results show that the executive branch, which is the power that makes public policy, seeks to establish, in general, a public action that is comprehensive and addresses the many sectors of society. If a country develops strategies for public policy plans, it means that it understands that certain public positions, social investments and educating the population are important for developing a more just and humane society. By designing public policies the state chooses certain values that need to be reinforced, disseminated and respected.

That is the point at which the state starts contradicting itself. The constitutions of the studied countries either directly or indirectly provide for the right to equality, freedom from discrimination, dignity and privacy. That is to say these countries have chosen these values as fundamental ones to their societies and wrote them down on their constitutions, the highest-ranking law in a nation.

In almost every country in the study it has been observed that while states consider non-discrimination to be a fundamental value of society, they also have laws and practices in public policy that discriminate against certain groups. This is what happens with the previously mentioned immigration issue. There is no consistency between the public policy made by the Executive branch and the rules defined by the Legislative: they clash, thus giving rise to situations of rights violation by the state.

Another common contradiction between public policies and the law is related to vulnerable populations such as that of IDUs. Public policies established as a result of the emergence of AIDS determine the participation of civil society in their development, including PLWHA, TS, LGBTTTI, but almost never IDU.

The laws on the rights of these key populations do not guarantee rights; rather, they determine discriminatory attitudes by state agents who violate rights (the obligation of identification card for sex workers, denying the right of marriage for same-sex couples and the prohibition for them to adopt children).

The paradox lies in the fact that the state itself prohibits discrimination while determining it by law.

The lack of harmony among components of the state also includes the judiciary, although this very same branch has leveraged changes regarding the rights of PLWHA in many countries. For example in Brazil, El Salvador and Colombia, many court rulings were based on the constitution and determined, among others things, the right to antiretroviral drugs where this right had already been established by law.

The lack of harmony between the executive, legislative and judiciary branches shows how different their conceptions on human rights, the right to health, the right to non-discrimination and other rights are. The resulting discrepancies may cause instability for people who need to have their rights guaranteed.

It is important to analyze how to realize rights using means other than the law when this fails to promote them specifically. Two examples on same sex marriage legislation illustrate this situation in Brazil, where these marriages are not legally recognized. In the first example, the National Immigration Council issued a rule that allows foreigners in a relationship with Brazilian nationals to apply for permanent residence in the country. Also in Brazil, the Social Security Institute has found a person eligible for partner benefits regardless of gender. Even though there is no law requiring social security to grant this right, a court ruling forced the Brazilian Social Security Institute to recognize same sex relationships for purposes of social benefits. A final example is the Law on Domestic Violence against Women (Law 11,340 of 2006), which contemplates women who are victims of household violence regardless of their sexual orientation.

Disagreements between state branches raise the following questions: Is a specific regulatory body absolutely necessary for public policies on HIV/AIDS to be effective? Or, in some respects, does the existence of a regulatory body in the state allow for actions that promote public policy effectiveness? Further investigation must be conducted in each country to answer these questions, since each country has a very particular set of legal rules with their legal specificities.
In view of the aforementioned situations, would it be realistic to conclude that States are in a transition phase from health policy values that are typical of a time riddled with fear of transmission, to policies that respect the rights of people in society? According to the two surveys, they appear to be halfway between the two alternatives.

It is also important to consider that omissions and contractions within the state itself can, in many situations be an obstacle to prevention and treatment, in addition to allowing for stigma and discrimination. An important conclusion is that actions by civil society were instruments to initiate and develop the rights of key populations. The study revealed that responses on this issue vary in the countries and still leave gaps in the field of public policy and rights that need to be bridged with the support and initiative of civil society, since the role of the judiciary was and still is fundamental to guarantee the successes achieved and serve as an instrument for the realization of new rights.

In this sense, it would be important to analyze the relationship between public policy effectiveness and the presence – or absence – of laws guaranteeing the objectives of this policy and identifying the settings where advocacy actions can be directed toward the attainment of these objectives.

**CHALLENGES TO PUBLIC POLICIES AND THE GUARANTEE OF RIGHTS**

The study shows that it is still necessary to promote changes in public policies regarding the rights of PLWHA and other vulnerable populations. Among them are:

- To promote the mainstreaming and use of international treaties in each country’s domestic legislation, so that they can be effective tools against violations of the rights of PLWHA and other populations, since they contemplate many rights that can help recognize a person’s dignity, especially of PLWHA and others in vulnerable populations. In some countries treaties have the same status as the Constitution and in others they are at the same level as national laws. It is also essential to guarantee the right to non-discrimination in laws under the constitution.

- To establish a sexual education public policy and change the religious influence in determining its content, especially in the case of secular states whose constitutions guarantee religious freedom. In those States with a sex education policy in place, this should be strengthened so that its coverage increased.

- To make laws banning layoffs based on discrimination and, in case these layoffs do happen, make it an obligation of employers to prove there has been no discrimination. Concerning this proposal, it is important to highlight that legal proof means are not the same to the parties before the court, an inequality that stems from the very conditions and context of the fact under analysis.

- In relation to sex workers, it is essential to review the concepts that may cause the criminalization of their behavior so that definitions such as “acts against public decency” and “morality” are not open to interpretation by state agents, as this in many cases leads to discrimination. In other words, the legal text must be reviewed so as to prevent it from being interpreted on a subjective basis.

- To follow up on the making of laws concerning the interests of key populations, allowing for rules that are more effective in protecting their rights.

A recommendation based on the situation of the analyzed legal frameworks is to promote the training of lawyers and/or public defenders so they can take the issues of rights violation to courts. That will lead to rulings that will strengthen the law and force the disclosure of achieved rights. For this to happen, agreements must be made with bar associations, representative institutions of prosecutors and all those who directly or indirectly work and care for the rights of key populations.

Finally, the results of the study make it possible to say that Latin America is in a transition phase from health policies based on fear of the illness to policies that guarantee the rights of PLWHA and other key populations. In this sense, it is still necessary for health agents to strengthen this commitment and make further efforts to increase and maintain key population access to legal services. The next steps, which go beyond maintaining what has already been achieved, must move towards guaranteeing human rights for every individual so that, in times of fear, stigma and discrimination are things of the past that do not linger in the present.
The HIV/AIDS epidemic is a good opportunity to show how these alliances can be productive – especially those related to PLWHA and other key populations, which are those that really work on prevention with their peers. This chapter focuses on the relationships between the state and civil society, with an emphasis on access to resources and services and the continuity of actions currently under way. The analysis is based on the results of interviews conducted by the Alliance.

Regarding organized groups, information from the study shows that political action has contributed to improve civil society participation as well as its dialogue with government. Also, key population actions in the past few years can be interpreted as a milestone of their achievements to the extent that such achievements are the result of their participation, lobbying and influence in the laws, which contribute to consolidating rights and have an impact on national response. Nevertheless, this does not mean that CSOs are always consulted by governments, that partnerships are a routine, or even that policies are always favorable.

An example is that while LGBTTTI and sex workers have conquered more space and recognition in the fight against HIV/AIDS, policies remain contradictory at times. While some government policies aim at fighting discrimination against PLWHA there are institutions that insist on discriminating against other key populations such as LGBTTTI and sex workers (FLACSO, 2008, pp. 75 and 84). This is not the case for throwing groups against one another, but it is important to note that policy making is influenced by social representation, what may result in rejection – even if sometimes unintentionally.

For governments, working in cooperation with PLWHA and other key populations seems to be important, particularly considering that there are areas governments are unable to reach and populations that are consequently out of reach. Another relevant factor is the possibility of making mass policies and campaigns aimed at these populations that make it possible to convey prevention messages in a way they can understand.

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4. Advocacy, called incidencia política in Spanish, is at its most basic definition “a set of actions aimed at decision makers to support a specific political cause.” (Alliance, 2008, p.3)
THE ROLE OF KEY POPULATION NETWORKS

OSC advocacy has evolved and acquired new expressions as a result of networking. This has brought changes to the CSOs themselves, as well as to their relationship with the state at different governmental levels.

CSOs are in a context that requires them to act politically and at the same time implement programs and maintain themselves. In the area of HIV/AIDS, both aspects require dialogue with the government since both the government and society have essential roles in the response to the epidemic.

Among CSOs, the rules of the game lead to a paradoxical situation in which they have to compete for the available resources while cooperating to act on the situation PLWHA and other key populations live in. This is why networking is so important. CSO networks have action strategies for CSOs, generate and share information, build the capacity of their members and strengthen collective power when the need to negotiate with other social actors. Some CSOs are very active in this process, while others are dormant or even close to extinction.

Nowadays LG, Trans and TS networks are on the rise in what seems to be the result of the visibility acquired due to their position on the international HIV/AIDS agenda. According to Figure 3, 80 out of 100 organizations interviewed by the Alliance belong to a network. Furthermore, among the key populations interviewed MSM (96%) is the one with the highest level of participation in networks, followed by PVP (78%), TS (87.5%), Trans (64%) and IDUs (60 %) (The Alliance, 2008, p. 26). This shows why MSM organizations have considered networking to be so important.

The participation of networks in decision making spaces has become increasingly necessary. Generally, network representatives are in national spaces, what is considered important since this makes it possible to include small organizations in the political debate and generate, for instance, joint training. However, each key population has its own dynamic.

Virtually every country among those studies has a national network of PLWHA organizations or individuals. This is also true for other key populations, except regarding regional networks: the Red Latinoamericana y del Caribe de Personas Trans (RedLacTrans), the Red de Trabajadoras Sexuales de América Latina y del Caribe (RedTraSex) and the Coalición de Organizaciones Gays de Centroamérica (CONGA).

Figure 3: Distribution of organizations according to network membership and primary target population

<table>
<thead>
<tr>
<th>Network</th>
<th>Primary Target Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSM</td>
<td>23</td>
</tr>
<tr>
<td>TS</td>
<td>23</td>
</tr>
<tr>
<td>Trans</td>
<td>16</td>
</tr>
<tr>
<td>IDU</td>
<td>11</td>
</tr>
<tr>
<td>Several</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
<tr>
<td>PVP</td>
<td>18</td>
</tr>
</tbody>
</table>

It is also clear, according to Alliance results, that belonging to a network is a key factor to guarantee a greater mainstreaming of organizations into decision-making spaces. This is why networks are an important source of influence, power and social capital. In this regard, 73% of MSM organizations, 62% of PLWHA, 50% of TS, 36% of Trans and 33% of IDU organizations reported having participated in the design of National Strategic Plans (NSPs) currently being promoted by the UNAIDS to comply with “Three-One” principles. However, it should be noted that participation is more focused on NSP design than on implementation and evaluation.

Networks and organizations have the same concerns with respect to the requirements or advantages of having legal status. Note that, in Brazil, network projects with government support are sometimes the legal responsibility of organizations, but there have been times when CSOs asked about the possibility of giving legal status to a network or forum when dealing with a projective organizations (key populations or CSOs) are collectively interested in. Sometimes, organizations and individuals, as in the case of the Brazilian Prostitute Network, do not have separate legal personality and their projects are submitted on behalf of another organization.

Another example is the Network of People Living with HIV, with many nuclei throughout the country. Some of them have personality and some don’t. Most of the HIV/AIDS forums have legal personality.

The federal government – and some state governments – also provides financial support to political activities like the National Meeting of HIV/AIDS NGOs, the National Meeting of People Living with HIV/AIDS, Network meetings, etc. State and city administrations are encouraged to do the same. This does not solve the whole problem, but encourages political debate among organizations, regardless of technical information and organizational challenges. Organizations discuss political confrontations, representation in cooperation spaces and relations with the three government branches and other potential partners.

It is also important to address the difficulty of CSOs to generate new leaders. Some leaders have expanded their political networks and consequently their personal opportunities. While this may have been very positive for the individuals themselves, it also generates internal tensions to CSOs since leadership sometimes changes due to personal interests. In addition, there is no internal debate process concerning collective representatives whose responsibility is to proceed with their group’s political agenda and the respective relationship with the state.
GOVERNMENT RESOURCES AND SOURCES OF SUPPORT TO CSO ACTIONS

Analysis of Alliance data shows that organizations that belong to networks, especially international ones, generally have more diverse access to funding. Similarly, it has been mentioned that the strengthening of institutional networks has been explicitly included in some Global Fund-financed projects.

Since the mid 1980’s, national funding for HIV/AIDS in Latin American countries has been complemented by international funds. Civil society participation in projects, as well as multisectoral authority, is intensified by both state and international funding. Nonetheless, this new situation creates tension between management and advocacy that has developed into the pros and cons of participation.

To understand the problems of access to funds for HIV/AIDS in Latin American countries, it is important to observe how relationships between governments and CSOs are developed, as well as the relationship of actors with international cooperation agencies.

Most people interviewed believe that the government – particularly the federal government – is not providing CSOs with financial support. Therefore, there are no sufficient resources to maintain organizational structures. This last point seems to be a consequence of the position of foundations and funding agencies that, except for some international NGOs, prioritize projects instead of organizational strengthening.

This issue has been the object of international debate because some countries believe governments should provide CSOs with resources. CSOs, in turn, argue that governments should fund their work as this has been done mostly through international cooperation. However, it is important to say that in Brazil, for example, there is a clear agreement that CSOs have the right to use public resources for their actions.

The organizations that participated in the study are given different types of financial support. However, most times this support is not much and money is therefore not always available due to formal impediments (as in the case of the United Nations) or to limited resources, as in the case of individual donors or organizations.

Umbrella organizations are another relevant aspect. The study shows that some entities try to solve the financial problem by choosing an “umbrella organization” to manage funds for organizations working with key populations, particularly those with no legal personality.

In principle, this allows an organization facing technical and formal limitations to receive financial support and funding, but since relationships are not isolated there is criticism regarding reliance and hierarchy among organizations. “Recipient” organizations are given little opportunity to grow and develop because they no not have resources for organizational strengthening, as pointed out by an interviewee: “We end up as mere recipients, but I can’t see our organizations becoming stronger in our communities. We’re always under umbrella institutions. We’re under dripping umbrellas”. (the Alliance, 2008, p. 38).
In this sense, it would be relevant for fund providers to invest in developing qualitative participatory methodologies, with the objective of evaluating the work of these movements, especially sex workers, IDUs and Trans. They perhaps cannot, do not know how to or do not like to manage formal processes, but are well organized politically and work closer to their peers.

Another situation that deserves attention is that some groups want to have legal personality not only because of project funding but also to be present in formal negotiations and express, by means of institutionalization, greater social relevance. This shows that the link between access to funds and the possibility of occupying decision making spaces is a factor that increasingly blocks the mainstreaming of key populations, which are usually either excluded or poorly represented.

There has also been reference to some organizations that were created almost exclusively for funding purposes and are using opportunities to participate in decision-making processes. This means ignoring important aspects that are important pillars of CSOs, like their institutional mission, from which their commitment and public recognition derive.

In the information gathered by the Alliance, it is interesting to note that there are two types of organizations in respect of their source of revenue: those that are supported by international cooperation and those that rely on individual member contributions.

Most of those that depend on international cooperation, except Mexico and Brazil, count on the GF project, though in different ways. Some interviewees have said that, in parallel, there was an increase in government resources.

Another important point is that with the entry of GF resources, many cooperating agents have withdrawn, especially in the Southern Cone. Domestic resources have also been reduced in the area, which highlights the lack of funding for CSOs.

Key population organizations have limited access to resources, from knowing how to manage a budget in dollars to designing different projects. Even when interviewed agent representatives say requirements can be generally met, key populations have impediments to do so.

Another aspect is that CSOs are known to do volunteer work, but the study calls attention to the fact that working with HIV/AIDS involves the “motivating” aspect of “life and death” and points out little professional training in some key population organizations in order to do the job. Considering this, the following are important challenges:

- Develop technical and resource management capacity among key populations through training.
- Make strategic alliances between more established organizations and those in the process of empowerment.
- Learn to work together and not try to cover all projects: break down into areas of competence.
- Extend to other funding sources, which are not only local but the ones at hand (the Alliance, 2008, p. 41)

**ACCESS TO RESOURCES AND EFFECTS OF THE GLOBAL FUND**

According to the survey, access to resources is a pervasive issue in most countries – particularly given the presence of the Global Fund – as are the effects of financial and political relations. The Global Fund to Fight AIDS, Tuberculosis and Malaria was created in 2001. The establishment of this project funding mechanism is innovative because it is a multilateral initiative for health that brings together governments, civil society, the private sector and PLWHA. These programs are designed and governed at the national level through a mechanism of multi-sector partnerships (public and private). The GF raises funds to expand the responses in prevention, treatment and care for PLWHA, Tuberculosis and Malaria in the most affected countries, those in economic disadvantage and those where one of the three diseases may grow rapidly.

Positive aspects of the GF include the fact that it promotes relations across different sectors and values the role of key populations in decision making.
While it is positive that GF funds are of a long-term and abundant nature, their predominance in the national scenario is dangerous because it leads to the assumption that the GF is the only way to have access to funds. It also widens the gap between those who have access to funds and those who don’t.

The possibility of obtaining funds from the GF has been an opportunity for countries and CSOs, but it has also generated great concern about the sustainability of government programs as well as – directly or indirectly – about the role of CSOs in their national scenarios and their own sustainability. One concern is based on how the actions initiated by GF projects continue to be implemented and included as accountable for the epidemic in government responses.

This results from the fact that many times GF MCPs organize their projects regardless of national strategic plans, which go against the GF principles of harmony and coordination. In general, there is no coordinated work so that national needs will not be ignored and a sustainability-oriented vision will be attained. In turn, parallel funding makes governments refrain from investing in the national response to the epidemic, particularly in respect of CSOs actions with key populations.

The study shows that the Dominican Republic and El Salvador are the two countries that rely on external resources the most. The case of the Dominican Republic is especially worrisome because a state agency has been created to manage GF resources. The Dominican state then takes over the responsibility for managing ARVs, while neither the state agency nor the funding itself is underpinned by a legal framework.

According to Mexican civil society organizations, international funding has changed and government support has increased. We can say that Mexico is the only country in the study that has not yet received GF funding. In addition, for financial support to CSOs only the governments of Mexico and Brazil have called public bids. In Brazil, the process is decentralized and coordinated by the states and some municipalities.

In general, PLWHA organizations have had more access to funding sources, so they have higher sums available as compared to other key populations.

This result is connected to the history, the epidemic pattern and the age of PLWHA organizations – which started in the 1980’s with no funding at all and gradually obtained more financial resources. It is important to point out that international funds – particularly the GF – have prioritized key populations lately just as they did with PLWHA in the beginning of the epidemic. It is also clear that UNAIDS has created robust strategies to help funding key populations in the last ten years, especially for MSM programs and participation. Nowadays, TS and Trans are also expanding their participation.

It is often said that political actions used to be stronger prior to GF funding. However, there are no elements to state that, as the GF is part of a broader political scenario and its repercussions are specific to each country. An analysis of the research suggests five challenges related to the Global Fund:

- The consequences that may result from exclusive financial reliance on GF resources to address the epidemic, on the part of both the government and civil society organizations (except in Mexico and Brazil).
- Changes in relationships that occur or may occur in the partnership between government and civil society following inception of the GF.
- The need to monitor the risk that the Governments will reduce their investment and accountability in the response to HIV/AIDS because of external financing.
- The politics of participation of CSOs in MCPs, to ensure that it is actually a possibility of cooperation with other social actors in the field of HIV/AIDS and values the demands of key populations.
- The fact that key populations now have the opportunity to obtain resources to implement their work and make it visible but, at the same time, they are trapped in formal requirements (legal status, project plans, monitoring and evaluation) that sometimes change their profile or action.

GF program funding is basically supporting many key population organizations, with differences in access to such funding. Access to a funding source is a positive aspect, but it can be negative at the same time because organizations are restricted to a single funding source.
The fact that this is a positive support may be a pretext for promoting dialogue with the government to make it evident that both these actions and the transfer of financial resources are important to maintain.

This would lead to gradual institutionalization and the possibility of not disturbing the dynamics of social confrontation and control of HIV/AIDS together with key populations.

CSOs have said in the interviews that the requirements for accessing GF resources by some major recipients limit the access of some organizations. One of the main causes is the requirement of legal personality, followed by evidence of experience in managing budgets and, finally, the ability to design and implement projects. While there are requirements that are sensible to fund providers, it is advisable to consider the limitations they impose on key populations. There is also a risk to always fund the same organizations that meet the requirements to come up with good projects but are not always in touch with the reality of key populations. Project logic imposes limitations on CSOs, but it also means status, recognition and access to the “world of authorities”. In this sense, it is interesting that governments begin discussing other forms to transfer funds and/or monitor the work of funded CSOs.

The study concludes that factors that contribute to different participation of key populations include geographical location, network membership and organization profile (legal personality, technical capacity, access to resources, etc.). In short, while participation may be an improvement there are challenges such as the persistence of participation that are either not institutionalized or have no clear or limited rules. Still, identity and location are generally the central elements in articulating social movements. The survey shows this by demonstrating that regional –and sometimes sub-regional– key population networks have contributed to build capacity, communication and advocacy in the international arena, with an impact at national level. Networking enables simultaneously conducting dialogues in the international scenario and at provincial level, so that a movement in both the local and global scenarios is evident.

From the perspective of CSOs, it is important to say that advocacy and legal registration are not incompatible. In fact, catering for an immediate need whose mission is not clear –sometimes there is no clearly stated institutional mission– causes groups that are not well consolidated to change their status in no time and take other commitments. This is how the fundamental challenges of CSOs –like monitoring public policies, preparing proposals and developing an agenda that is different from that of the government– get mixed up and weakened.

It is alarming that some CSOs are increasingly concerned about and engaged in implementing measures related to technical projects, sometimes with interests that are primarily governmental, losing focus and dedication to develop advocacy actions and do their job monitoring public policy.
On the other hand, funding policies prioritize social activities and interventions but do not necessarily support organization strengthening and do not invest sufficiently in monitoring and assessing organizational settings where the work is done. In this sense, policies monitor but the performance of activities for which there is no guarantee of continuity. This, in turn, creates instability in the budgets of CSOs.

Legal personality is a form of regulation that not only enables access to funds, but also guarantees formal commitments and drives organizations into public actions. Actually, two very important issues to organizations are in debate: their political expression and the need to have “technical expertise” that can guarantee maintenance of their actions as well as of the organizations themselves. This also mixes public commitments with the private interests of individuals who hold certain positions but sometimes are not clear on their roles as collective political subjects.

The idea of belonging to a collective and mutual trust necessary to establish linkages to enable them to exist as such, still seem fragile in some key stocks. This makes them stronger or weaker as a group, according to the debates in their countries, but also offers them a better chance of building their own political agendas. The idea of belonging to a collectivity and the mutual trust necessary to establish connections that allow them to play this role still seem to be fragile in some key populations. This affects their collective strength according to debates in their respective countries, but also gives them more opportunities to come up with their own political agendas.

The whole scenario described above has been generally present in the central arenas throughout the countries, and has been gradually transmitted to provinces and municipalities. In some countries, there are formal spaces for CSO participation at provincial and local levels due to general decentralization policies, particularly in respect of health services. According to the survey, this is less frequent in Central America and the Caribbean. These variations also generate changes in the profile of representations.

According to the study, there is a wide variety of financing types. Virtually as CSOs are given external funding, with specific differences for each key population. External funding can be international (foreign governments, individuals, bilateral cooperation organisms, churches and international NGOs) or can come from a range of domestic sources, and not always in cash. Domestic support is generally provided by federal and local governments, unions, private initiatives, national foundations, isolated individuals, large organizations and the sale of specialized services or products (Alliance, 2008, p. 37).

Figure 4. Percentage distribution of organizations by size of income

Source: Alliance / INSAD. Qualitative research: political participation and access to resources by key populations in ten Latin American countries. Jul., 2008.
Although the sample is not representative of the region and the countries themselves, and considering that the source of information does not take into account records but rather information provided by respondents, it is possible to estimate the distribution of resources among CSOs. It can be inferred that the amount of financial resources is related to the size of the organizations and the coverage of their work and services. The data presented in the following figure shows that 55% of organizations have maximum annual budgets of $150,000 (USD). Among them, 28% have budgets of less than $50,000 and 27% between $50,000 and $150,000.

The three intervals over $150,000 have few percentage differences: 12% of organizations have between $151,000 and $250,000, 8% between $251,000 and $500,000, and 10% over $500,000. Also noteworthy is the fact that the percentage of organizations that have no funding (15%) is greater than that of those with more financial resources.

Despite the variety of sources, funding does not come in a large volume but for a few exceptions. Some organizations count mostly on international cooperation whereas others rely on their own members for funding. Many organizations are not given external support and local organizations almost always count on local funding only.

It is widely recognized that PLWHA and key populations are central to actions in response to HIV/AIDS. All strategy and outreach to these populations depend on CSOs. In this sense, it seems necessary to discuss two important issues. First, that financial resources from donors - governmental or otherwise - should also be intended for CSO organizational structure issues such as training and monitoring, and not only for executing project activities. CSOs, in turn, should have a critical mind when analyzing how they have been managing projects.

Research carried out by Alliance highlights some key population advances in access to resources

- Over the years, some CSOs have gone through a process of institutionalization that ensured them access to resources. While linked to economic issues, this qualitative change does not depend on them solely, as the work of CSOs work is underpinned by a commitment that includes the condition of their belonging to a group affected by or vulnerable to HIV.

- Networking, in addition to being a highly political strategy is also used with different results as a tool to reduce differences and promote access to the necessary financial resources – both to strengthen organizations and to increase effectiveness in responding to HIV/AIDS.

- The urgency in addressing economic needs has led some CSOs to create innovative survival strategies that in spite of not achieving full organizational maintenance do seem to strengthen their decision and commitment to maintain their contribution to the collective response to HIV/AIDS.

- Although strategic perspective and the capacity of considering funding options other than international cooperation and scarce public money are not common, there are some cutting edge organizations that are starting to consider involving other actors, like private enterprises, in the response to HIV/AIDS.
The following challenges and opportunities are based on how to build on achievement, gap analysis, changes in the context of the response to the HIV-AIDS epidemic and international cooperation actions. Furthermore, they're based on international human rights instruments and on the elimination of all types of discrimination that have been confirmed by UN member countries as the Declaration of Commitment of the Special Session of the General Assembly (UNGASS), which includes provisions that prioritize HIV/AIDS prevention actions by defining and assigning responsibilities to public institutions and CSOs.

Historically, the response to HIV/AIDS in Latin America was built upon the notion that the magnitude of the epidemic could be increased by the situations of vulnerability experienced by some groups as a result of social, economic and gender inequalities. The epidemic has effects that impact on the quality of live of PLWHA and on social development in Latin American countries, with the ensuing economic, social and legal implications. In fact, despite the efforts made so far, the stigma and discrimination that follow HIV and the populations most affected by it, remain as the greatest obstacle to the effective development of support, prevention and treatment programs. Most CSOs insist with governments that it is necessary to continue working to guarantee human rights, particularly to populations that are most discriminated against and deprived of legal protection.

To do that, international cooperation must provide technical and financial assistance that strengthens and supports CSO advocacy and the promotion of human rights, like strategies capable of reducing stigma and discrimination and diminishing the impact of the HIV/AIDS epidemic.

It is not absolutely true that laws result in economic and social change, but it is possible to say and infer that they have played an essential role in backing up favorable policies. That is the case of the law that guarantees access to treatment, which in the cases of Brazil and Chile are a clear example of how specific legislation can help strategies to care for and treat PLWHA. That is why it is necessary for governments to encourage their Legislative and Judiciary branches to create cross-sector policies and improve legal systems that are usually saturated and inefficient.

Civil society organizations, supported by international cooperation, need to strengthen actions that enforce the law, promote awareness programs and train professionals working in the judicial system. Information and legal assistance programs are fundamental to promote and guarantee the rights of key populations, based on the laws and policies that have been conquered so far and on opportunities provided by laws that are already effective, as in the Brazilian case. It is also important for legal professionals to have a less specialized and segmented perspective of their job. For instance, some are very knowledgeable of HIV/AIDS legislation but do not know labor laws or the other way around.
The challenge is to protect key population human and civil rights to ensure that they have the same opportunity for prevention and treatment as the general population. Multisectoral actions involving civil society and international cooperation are still needed to promote public awareness of the need for preventive strategies such as sex education, reproductive health and safe sex, among others.

The fact that Latin American constitutions establish the right to health has helped develop these rights in spite of ups and downs in some countries. There are three major accomplishments in this area: the restoration of the universal right to health, the change of the legislative trend by growing specificity and decreasing obligation, and the recovery of the state as a central actor and guarantor of human rights.

Analyses of the legal framework point to the need for stronger actions to overcome legal prohibitions that still exist in some countries in respect of homosexual males, sex workers and users of injecting drugs, as they’re are subject to penalties in many countries. This makes these people more vulnerable to contracting HIV, particularly when fear of sanctions make it more difficult for them to identify themselves and participate in group activities, harm reduction programs and public activism.

For key populations, the primary problem is the stigma. In some countries you cannot write the words gay, trans and sex workers in documents aimed to formalize their organizations because these would be denied legal status. Stigma is sometimes openly expressed. It is necessary to show the state, which seeks to fight discrimination, the permanence of laws that hinder the exercise of citizenship and the guarantee of rights.

Among the rights investigated, the right to sex education is one of the biggest gaps for vulnerable groups. The contents of sex education depend on the possibilities of each country. A tool that could be used by CSOs is debating and reflecting on essential or non-negotiable actions for an international political agenda, like talks on abortion and sex rights, for which there is a common parameter in the global scenario that serves as input for organized groups. Access to accurate information is essential to confront fundamentalist religious wings.

The discourse of actors in response to the HIV-AIDS epidemic evinces that the region is still in need of laws and priority political actions:

- Public policies for access to information and sexual education.
- Legislation to punish the violation of the right to privacy and non-discrimination with respect to privacy and confidentiality in voluntary counseling and clinical tests.
- Litigation strategy: submission of legal jurisprudence in an attempt to compel the legislative to act quickly on judicial reforms.
- Laws to fight discrimination and policies to fight stigma.
- Laws and policies on sexual and reproductive rights, so that decisions can be made without coercion, violence and discrimination and access to safe services and information can be promoted.

CSOs need to find and promote specific mechanisms to prevent and combat discriminatory actions. Organizations need legal support. This does not mean they need to have legal counseling services, but rather that they should seek and commit legal entities to working in the defense of citizens.
The study this document is based on investigated topics related to human rights in Latin America, as well as the advocacy and participation of key populations. The results point to the following question: “How can civil society organizations use the participation conquered to qualify and strengthen advocacy and make democratic alliances with the government?” The answer must consider that CSOs still have to exert monitoring and social control in Latin America so that laws are favorable to PLWHAs and other key populations and contribute to developing policies.

For PLWHAs organizations and networks, it would be important to consider intersections between HIV/AIDS, sexual and reproductive health, reproductive rights and sexual rights in the field of Human Rights, at least by two paradigmatic situations. First, women who live with HIV and their partners want to have children in a social context in which this option is considered either impossible or reckless in view of the risk of vertical transmission. Second, the difficulties concerning the implementation of the right to privacy, as shown by the study. Violations of this right have been reported, as shown by the case of testing without the consent and sometimes without the knowledge of women.

Social networks should consider the opportunities provided by laws on decentralization and municipal responsibilities to promote human rights laws and policies, especially rights to health, non-discrimination, privacy and sex education.

This would help strengthen the involvement and action of network hubs that are not centrally located. A current challenge is to achieve greater civil society representation from all regions in a country and their specific problems, thus fostering more inclusive representation. It is also necessary to overcome a trend to centralization concerning fund distribution. Decentralization would help extend the response to HIV/AIDS to other realities that are scarcely reached nowadays, particularly those located far from political and debate centers. At the same time, it is necessary to promote the development of accountability mechanisms to the represented sector and the renewal of representatives (these processes usually do not count on funding).

The participation of PLWHAs networks and LGBTTTTI groups has increased with policies, laws and new cooperation mechanisms like the Global Fund, which has succeeded in being mainstreamed into the development of national HIV/AIDS strategies in many countries. It remains a challenge to increase the participation of all key population organizations, including TS, trans, IDUs and Gay/MSM.

It is also important to consider that this involvement has yet to overcome constraints such as the lack of participatory mechanisms that go beyond representation and capacity building to act more strongly and effectively. In addition, it is important to highlight the need for more balanced and effective representation in spaces like the National Coordination Mechanism or the National AIDS Councils, since in some cases intergovernmental agencies and the Government have a determining influence on decisions.

The greatest challenges to CSOs are sustainability and funding source diversification, for they rely heavily on international cooperation – the GF, for instance. Overcoming this vision is a challenge not only for CSOs but to governments as well. In this context, it is essential for organizations to get governments to see their contribution as substantial, so they can become partners of the government.

Governments must maintain their responsibility to fully protecting the prevention and treatment of HIV/AIDS at national, provincial and municipal levels. They also need to honor commitments, meet international goals and carry on with processes implemented to support international cooperation and funding mechanisms like the Global Fund.

It is imperative that CSOs are able to develop projects based on continuity and sustainability. To get there, they need to be made stronger as regards raising funds from a larger variety of sources. Similarly, projects must be connected to organizational structure and vision in their planning, monitoring and evaluation so that realistic sustainability goals are created and followed up on. Community systems could be improved by more solid organization management, as well as by having governments come up with and define different ways of transferring resources to CSOs and monitoring their programs.
Another challenge is to count on HIV/AIDS councils and, generally, cross-sector decision making mechanisms that work effectively rather than simply meeting the requirements of fund providers.

CSOs must continue to play an active role not only by executing projects, presenting diagnoses and interacting with governments at the program level, but also by participating in proposing solutions and positioning themselves as political actors. CSOs must go beyond sheer presence in arenas to presence in documents, and evolve from participation to stronger influence in decision making, so they can respond cohesively as civil society, with greater consensus about objectives, problems and solutions. In this sense, greater cohesion, trust and solidarity in discussing relevant issues are required. All these factors could lead to increased possibilities of access to resources.

As far as international cooperation is concerned, it must be considered that the HIV/AIDS scenario has changed and that challenges concerning human rights and policy making should be updated accordingly in the Latin American context, which has many similarities but also peculiarities to each country, as the study clearly shows. It is then important to make sure responses take into account regional disparities and the strength of decentralized alliances, encouraging and monitoring cross-sector public policies and broadening key population access to information and the legal system. Finally, it is not enough to develop human rights indicators; it is also necessary to promote and generate commitment and capacity in social actors so they can monitor their own compliance with these indicators.
ANNEX

FIRST CASE
PLWHA IN THE PROCESS OF ACCESS TO ANTIRETROVIRAL TREATMENT BEFORE 2001

SECOND CASE
PLWHA IN THE PROCESS OF ACCESS TO ANTIRETROVIRAL TREATMENT UNDER THE HEALTH REFORM AND THE AUGE PLAN
The purpose of this study was to provide an overview of the perceptions of people living with HIV/AIDS and antiretroviral drugs in Chile. It is about getting to know, from a particular fact, a more complex phenomenon in relevant circumstances in a specific context. The data collection technique used included detailed interviews with PLWHA to understand, first, the process of access to antiretroviral treatment before 2001 (when the Chilean PLWHA movement forced the state to provide ART) and second, the processes and health dynamics in supplying drugs, with the emergence of the health reform that introduced the AUGE Plan.

A qualitative methodology was used with a focus on case studies suitable for providing information on subjective experiences and documenting the way people interpret, understand and define the world around them.

The findings of the case study answer an important question: What are the differences in PLWHA’s perceptions of the access to antiretroviral treatment in different political, historical and social contexts? To answer this question, we analyzed the interviews based on four fundamental rights that are part of the overall investigation: the right to health, the right to information or education, the right to privacy and the right to nondiscrimination.

As the selection of cases must be typical or representative of other cases in order to provide an understanding of the phenomenon under study, two PLWHA were selected: one that has been taking medicines since 1998 and another that has been receiving treatment since the end of 2007.

The study included content analysis, which involves identifying, coding and categorizing primary patterns in the discourse of interviewees. The meaning of specific paragraphs was sought in the context of all data and an appropriate category was determined. Data were coded by identifying phrases, themes or concepts in interviewee text/discourse in order to identify and analyze the underlying patterns based on four pillars: the rights to health, privacy, information and freedom from discrimination.
As a key measure, the proposal was to ensure that respondents were not adversely affected in any way. In this regard, the following criteria were established:

- Anonymity was guaranteed in all interviews. Surnames were not recorded. Tape interviews were labeled according to a code number.
- The purposes of the survey were informed.
- Information obtained was not used for purposes other than those of the survey.
- The conditions of the interview were informed: tape recorder and transcription.
- Privacy of the situation of individual interviews was guaranteed.
- Interviews were conducted by a researcher from the Gender Equity Program team at FLACSO-Chile.
- A consent was signed for each interview. A copy of the consent was given to the interviewee and another to the FLACSO-Chile research team.
- Interviewees were informed of their right to interrupt the interview at any time and to refrain from answering any question they considered invasive or felt uncomfortable with.

The following is the analysis of two cases of men living with HIV, with similar characteristics but different times as regards identification of the virus in their bodies, which means that access to antiretroviral treatment occurred in different historical contexts.

In recent years, there has been a host of changes in public health policies in Chile, specifically in the provision of full healthcare to people living with HIV. The cases presented here portray two different historical times, when differences in access to treatment and in the quality of the healthcare provided were observed. This situation produced changes that are evinced in the discourses of interviewees in terms of both their environment and perception.
This first case illustrates the first people living with HIV/AIDS in Chile and their access to treatment. It is possible to appreciate the social and political context in the early years and health response in its dialectic with civil society through the interviewee’s discourse. The analysis presented below is based on two legal areas: the right to health and the right to information and sex education.

A) THE RIGHT TO HEALTH

The right to health is now guaranteed by both the public and the private systems in the country. There are two health systems: ISAPREs, the private health service, and the National Health Fund (FONASA), which operates as a public insurer of the right to health. The AUGE (Universal Access with Explicit Guarantees) was established within the framework of the Health Reform implemented in Chile in the past years. The AUGE consists in the creation of a set of explicit guarantees for the exercise of the right to healthcare by the population at large with respect to claimability, opportunity and modality of certain benefits associated with some pathologies. Initially, the plan set 25 conditions, but the list more than doubled in 2006 when it totaled 56 conditions. Presently, the program includes 86 conditions. The elected pathologies are precisely those of greatest relevance and impact on the chances and quality of life of the Chilean population. The AUGE Plan, which considers diseases with the greatest social impact, began to be implemented in 2002. As noted in DIDES et al. (2006), the AUGE is a way to provide special coverage with the objective of reducing spending on catastrophic or very costly diseases. Thus, those affiliated with FONASA can only pay up to 20% of the costs of the disease itself and those classified as indigent or people older than 65 are treated for free. Attention to the requirements of conditions contemplated by the AUGE are supposed to be addressed within deadlines stipulated by the law.
Forms of access to antiretroviral therapy

In Chile, the right to health is in the Constitution. Access to antiretroviral therapy by PLWHA began to be provided by the public health system 1998, through monotherapy and bitherapy. In this regard, the interviewee mentioned that he first had access to antiretroviral drugs outside Chile – more specifically in Germany – where they were provided by an international insurance company. AZT (monotherapy) was the only drug available then. He says that upon his return to Chile he was included in the public health system due to an HIV-related crisis (opportunistic infections), to be given monotherapy as a complement to the bitherapy received in Europe, as described in the following account:

“I was covered by an international insurance when I was in Germany. So, they said I could do like my partner – Hartmut, my German friend – which was to get in touch with the insurance company and negotiate because it was in fact HIV and I had to take the drugs. They’d been giving me monotherapy, the famous AZT... I’d been taking it in Germany, but for a month, two months... actually, after a crisis. I came back to Chile for other reasons and forgot all about it until I needed drugs again, when I had a crisis here in Santiago, say, in 98, with pneumonia, pneumonitis. So they told me my defenses were very low and that I had a viral load of a million and needed triple therapy and so on... that was in 98.”

For a while, the interviewee had to get drugs from his contacts in Europe. This situation depicts the political and social context faced by people affected by the epidemic, who had poor – if any – care conditions and access to retroviral drugs.

Access to antiretrovirals in the public health system was granted in 1993. At the time, the system had waiting lists that caused it to operate poorly thus generating great uncertainty among affected people. A community network of organizations was created in 1991 to fight HIV/AIDS. These organizations have survived in spite of changes in their names and regroupings. In the Chilean case, it is possible to highlight that civil society has played an essential role in the struggle for access to treatment and against discrimination and stigmatization.
Clandestine drug sales – the black market – were big in Chile before universal access was granted. There were two reasons for that: first, people didn’t go to public health services because they were afraid of being discriminated against and stigmatized; second, those who did go to the public health system for treatment were either not given medication or put on a waiting list. According to the interviewee, drugs were too expensive and networks began to emerge as a result of the need to cope with the disease:

“I don’t remember exactly how much, but I could usually buy drugs for... eighty lucas ponte... the Crixivan, which was the most expensive one, could be bought for eighty lucas, sometimes ninety, more or less... then prices started varying because there were people who... when you got in touch with the Laura Rodriguez Foundation, they told you they knew about drug networks and some individuals had access to them... was there a Miguel something?, who was this kid who imported drugs.. or I don’t know if he imported them, but he did sell them here, that was pure business, it was.”

He says people who had medicines did not take them, but sold them for two reasons: failure to adhere to the treatment or resistance and the need of money to survive.

“What I did know is they didn’t take the drugs, or those were therapies that showed no result and people simply didn’t take the medicine and didn’t tell their doctors about it. After some tests they changed their treatment and whatever they had left was put up for sale, but in general... those were people who did not stick to their treatment, did not take their drugs every day, skipped here and there, put it all together and would end up with a full package of medicine at the end. You could save fifteen in a month, for example, you’d put them all together and sell them if you needed money... Particularly these, they sold them because if you didn’t like the medicine or if you had some sort of physical problem you’d just say I’m not taking this anymore, I want them to change it. Since it was not easy to get it changed, you’d quit taking them, protest and sell the drugs until they changed your treatment. That was a way of changing your therapy and taking the chance to sell it, to make a business out of it.”

With this information, it is possible to assume that waiting lists generated corruption and made it more difficult for people – especially the most vulnerable ones – to adhere to treatment. In addition, the drugs that were available in Chile were not credible for triple therapy because there was no such information from the attending physician and, for obvious reasons, the market did not give out all the information, leaving the intake of medicines to the user’s discretion.
Demanding Treatment from the State

It took this user approximately one year to get antiretroviral drugs from the public health system, what resulted in uncertainty to enter the protocol of the public health system, which guarantees full healthcare to HIV/AIDS-related diseases and opportunistic infections. This caused strong mobilization by PLWHA, who saw their requirements embodied in the submission of protection appeals:

“...Oh, I had to wait... let me see... it was 98 and the first drugs were ordered in 99, so it was like a year waiting for the medicines; one year getting them abroad. I also filed a protection appeal through Vivo Positivo against the state... those were the first appeals, but mine didn’t follow through, it was not well made, do you get it?”

The appeals were made in a context in which access to drugs was restricted. The interviewee says they had to make several protection appeals until general access was granted.

“We gathered people that were willing to stand up and do it... the protection appeal. I went but there was no result, but others went ahead and did get results, they opened the doors, let’s put it this way... When they gave access... there is a name, a legal name, what do you call it?... when the appeal was accepted, yes, when the appeal was accepted, access could not be just for a few, but for everybody.”

When asked about the process once the appeals were made, he says delivery was partial:

“No, it was... that is, I don’t believe the response to the appeal favored myself, because after the first people were given their drugs I got them too... they didn’t give the medicines to everyone at once, that is, I think somehow they pressed so I had my protection appeal granted.”

It is important to remember that the sanitary policy of the military dictatorship failed to provide official response to the emerging epidemic, particularly concerning Chile’s first case in 1984. Different social organizations worked with the gay community in prevention and education and, with conciliatory congressmen submitted a bill (1997–2001) and participated in the first proposal for the recently created CONASIDA (1990).

The situations above show a slow process that is still taking place in Chilean society, particularly in PLWHA and public policies expressed by the Ministry of Health’s CONASIDA. These efforts lead to envisaging – for the first time since democracy was reinstated in Chile – the possibility of a law being made by both civil society and the government. The AIDS law is the result of the efforts of social organization and members of Parliament. In this sense, protection against HIV/AIDS results from the social mobilization of the people affected. This is called a Citizen’s Law (Law 19779).
B) THE RIGHT TO INFORMATION

Treatment

In the early years of the epidemic, the information patients received was that on the regularity of medication. PLWHA and their families generally sought information by themselves or did it through social organizations connected to hospitals and started developing community interventions for self-care and adhesion to ARTs:

Before people started learning more about HIV, they always thought the end was death. When it became universal, I think people started to accept the idea that if they gave you drugs, and you didn't have to pay for them, you'd have to learn how to stick to the treatment and take care of yourself. Hopefully, they had a bit more information than before, being close to an institution like Vivo Positivo, where they had better access to information. But in this case I think most people didn't have the information.”

As for the provision of drugs during the administering and personal healthcare phase, the interviewee says he was given clear medical guidance and that the steps weren't complicated since they weren't entangled in the traditional bureaucracy of public health services. He also points out that the doctor/patient relationship was a good experience, particularly as regards adhesion to treatment:

“Uh... they gave it to me just like any other prescription drug... they told me I had to take it every so many hours, every eight hours strictly, so I had to find a convenient time. It depended on the time I woke up and then I'd count the hours to take them, the doctor told me so... I've always had... I've always been given good instructions, good prescriptions, I had no problems taking the drugs, that is to say I never took the wrong one. There were some I had to take on an empty stomach, for example, and I did so. I've always been very careful about that.”

At the beginning of treatment there were certain problems of drug availability. The interviewee remembers that sometimes the monthly dosage was no available, so he would be given a dosage for some time (weeks or days) and he'd have to back go to the hospital for more before those were finished:

“Yes, there's always been, it seems to me they gave partial dosage sometimes, for a while, and there was no more. Then you'd have to come in the middle of the month to get the rest. That happened sometimes, but in general they never failed to give me the drug.”

When asked about the treatment he began with, the interviewee said monotherapy came first, followed by biotherapy in 1994. This is historically related to the beginning
of new public policies for treating and preventing HIV/AIDS in the country and the struggle of PLWHA.

“I didn’t really consider the monotherapy. I don’t think it worked for me because in 1994, when they gave me bitherapy, I’d recently been diagnosed and that was the only one available, the only one they knew about. If there were other drugs I didn’t know about them, although I was in Europe... I didn’t know anything: I didn’t know the language, I didn’t know what I was taking... only later did I get to know it was AZT and that it was the only drug available then. But no, being abroad I didn’t understand the language, they gave me drugs and I took them, that was it. But I didn’t... I didn’t see any progress and I wasn’t even checked by the same doctor who gave me the drugs. At the time I was not evaluated to see how this monotherapy had worked out, how I was doing. So later on, when I came to Chile, I forgot about the whole thing, I actually wanted to... I was in the dark about it and forgot about it. Then my defenses got very low and I came down with pneumonitis as I told you... and then I had to go back to the hospital and start the procedure for them to give me the medication.”

The Ministry of Health’s CONASIDA has developed healthcare rules, which are contained in a 2002 Integral Healthcare Model. These are in accordance with the Ministry’s “Sanitation Objectives and Goals for the 2000–2010 Decade”. This model has been refined and updated to include new technologies as well as a human rights and psychosocial approach to full healthcare.

**Universal Access**

Patients who needed medication due to low defenses and high HIV load were given universal access to them in 1998. The interviewee’s perception of the changes and process related to universal access to treatment reveals a type of satisfaction that is not only economic, but also derived from the guarantees provided by public policies:

“...I think that was obviously good for everybody and it also makes people relax. It’s easier for many people who had already seen the issue was not about economics, but you could... you could have expectations in life, and people started learning more about HIV, which they knew nothing about, they always thought it’d end up in death. So, since it became universal I think people started accepting the idea that if they gave you the drugs, you wouldn’t have to pay for them and you’d have to adhere to the treatment and take care of yourself.”
When the delivery of antiretroviral drugs is universalized, a significant change is made in full healthcare to PLWHA. The interviewee, however, has the perception that there were no changes in the treatment process and in the quality of care. In his view, the changes refer to the way drugs were delivered, which was much more expedited, particularly as regarded the “place of delivery”.

“We'd go to the hospital pharmacy but to different booths, so there was no... we already had better access, easier, because that booth was more controlled or ... with certain pathologies... so it was not always as crowded as the regular ones. It was much easier to get the medications, and they have you on a log.”

One hundred percent coverage in antiretroviral treatment was reached in 2003. This new situation must be contextualized with the inception of the Global Fund in the same year. To date (2008), drug delivery and full healthcare to PLWHA is part of the Health Reform, particularly the AUGE plan, both for the public and private health systems.

**Current Treatment**

During the interview, the PLWHA who experienced both not having drugs given by public health services and moments when he had access to them states that healthcare has been adequate and effective. He also says there is more control of examinations associated with HIV and opportunistic diseases:

“Well, I have to see the doctor at least twice a year to take all the tests. With these tests updated, they'll give me prescriptions for three months of therapy, the same sheet but three times, which they take away until I have only the last one and they put the date of the next month I am supposed to go. I have to go within that date, sometimes I'm late, but the hospital won't accept more than five days of delay.”

Regarding application procedures and control of ART intake, the interviewee says in case of dropout or tardiness in retrieving medication, attending doctors and the health service exercise strict control:

“You see, if I show up five days after my medication is finished, I have to go to the nurse or to the doctor so they'll give me a certificate in order for me to be given the drugs again, i.e., for them to record in my file that I stopped taking the drugs for some time. They are actually making you go at the scheduled time.”
C) THE RIGHT TO NON-DISCRIMINATION

People who rely on public and private healthcare services in Chile do not always know they are both subjects and objects of healthcare. In this context, it is important to consider the relationship between attending doctors and patients resulting from the treatment, particularly in public hospitals. Regarding referrals to experts or the way other people looked at him, the interviewee complains he was discriminated against:

“Oh, it was unpleasant because everybody looked at you as if you were a freak, that is, everybody gave you the looks or put you in last, especially with referrals to proctologists or urologists... Or always... dentists... they would always see you last, they would say I had to tell I had HIV so they put me last in line.”.

In general, these spaces usually generate relationships of power in which orders, prohibitions and directions are expressed as threats to patients. On the other hand, it is also right – as pointed out by a study of Bravo, Pérez, Dides et al. (2003) – that the position of power in which doctors are placed gives them the power to relieve, assist and care for the ailments of patients.

Although changes in the care of PLWHA did take place, the interviewee mentions that in healthcare centers used by PLWHA, users who do not live with HIV see PLWHA as victims:

“What has changed is that people do not look at you with suspicion. They do not see you as... something... as a bad, negative person that can do them harm. They’ll see you as a victim and nothing more, that is, they’ll give you better care, the best way I think they could care for anyone.”

Concerning referrals, patients complain about the timing of referrals. The interviewee says there are no privileges or exceptions given to PLWHA. Equal treatment is given to everybody who uses public health services:

“Referrals to experts... yes, they do it... I think there is regular care, like anyone else; that is to say there isn’t... many times they ask for urgency, and exceptions can be made, but you have to wait when you’re not special, if there’s an opening a month later, you’ll have to wait for a month. That’s the way it is. There have been cases of people who need important tests urgently and if they don’t have them, you must do them privately to have the results because many times people are on waiting lists and... nothing happens... and you wait for a long time... not that it’s happened to me, I’ve been referred and promptly seen, I haven’t had any problems.”
SECOND CASE

PLWHA IN THE PROCESS OF ACCESS TO ANTIRETROVIRAL TREATMENT UNDER THE HEALTH REFORM AND THE AUGE PLAN

This second case is meant to contrast with the first one. Like the previous case, it is about a male of the same age, except for the fact that this interviewee had access to treatment under the new health reform – more specifically, the AUGE plan that gives explicit guarantees to PLWHA.

A) THE RIGHT TO HEALTH

The interviewee says he didn’t feel observed in any way whatsoever as he attended the public health service. In contrast with the previous case, he was rather an observer than the object of observation. In ten years, the symbolic position of the affected population had changed at least in one sector. It is possible to notice this as the interviewee says:

“No, I observed more, I was the one doing the watching… no, nobody looked at me. In fact, I was surprised to meet women, younger kids, gays, non-gays, drug addicts, you name it; it was an incredible variety… then I said… queers only, most of them, but there were all kinds...”

Access to Antiretroviral Therapy

At the time he found out he was HIV-positive, the interviewee says he showed no health problems and his lymphocytes (immune defenses) were at 210. In view of this situation, the doctor told him he should get started on antiretroviral treatment

“I learned about it in November 2007, that I was positive, this… was at 270 and simply went down to 210 when… in almost a year, I started the treatment for prevention… You’re supposed to start when you’re at 200, but I was at 210 and wanted to start at once because I wanted to be off the syringe so I did… er… Dr. Ballesteros saw me at the Salvador Hospital and he supported me, he was very supportive, nice and… I started taking the drugs that year… I’ve been on them for seven months and that was why, because it’d gone down to 210, that’s it.”
The delivery of antiretroviral drugs in Chile meets international standards, i.e. they are delivered to PLWHA showing lymphocyte counts below 200 and a viral load of 150,000 or when they have an opportunistic disease.

In 1997 – together with Côte d’Ivoire, Uganda and Vietnam – Chile entered a UNDP program to obtain preferential prices from the pharmaceutical industry. The agreement is still valid to date, and thanks to it and to the inclusion of HIV/AIDS in the AUGE plan, drugs are delivered free of charge.

“Antiretroviral treatment to HIV in Chile is a guarantee of the AUGE plan. It assures 100% antiretroviral coverage to adults and children that request it according to the national protocol; and 100% access to the transmission prevention protocol for pregnant women living with the virus.”

B) THE RIGHT TO NON-DISCRIMINATION

Cultural Discrimination

Enrolment in the healthcare protocols for PLWHA in both the public and private health systems must comply with formalities that we believe are too bureaucratic and complicated. To enter hospital centers, PLWHA must have an individual card that is delivered by primary care center (consultation offices) so that care protocols can be accessed. The interviewee’s experience account for a problematic situation since the process requires proof of residence and he did not live in the metropolitan area. He then had to provide a false address because he was afraid of being discriminated against and stigmatized:

“Well, that was when I registered with the program. That was complicated because as I was living… here in Providencia, I had to go to the office first and I had to get an individual card there… well, I am not from here, from Providencia, I am from outside Santiago, so wherever I went I couldn’t tell my story due to fear and prejudice and because I was afraid of losing my job and all that (...) a nice small town, so it was difficult for me to come and get the card at the office… they required it at the hospital I was registered to… so I went there, I told my story, I told them I couldn’t be cared for in my town, told them I worked in health care and they told me, say, finally in about two months I had a doctor’s appointment but then… that was the only one, I am telling you and that is little, I believe, when I started the treatment it was very fast, I told the doctor I wanted to get started and he supported me, and there I was within the month.”
Regarding the attention provided by the doctor and hospital staff, the interviewee says that in his case the people were very “friendly”.

“About the doctor, who’s the one I know most about, he was fine, very nice… he’s a very, very, very friendly type, has a very kind nature and a special sense of humor; we had a lot of laughs together and sometimes started singing; he’s a crazy character and I like that since I deal with artists… he likes arts and we got along very well. So, the other ones… no, no, it doesn’t matter much… they have good service at the pharmacy, I think all of them, all of them are very friendly; but in this case it’s about the doctor. He was the most important one to me, my doctor.”

**The black market**

Clandestine drug sales have decreased but not stopped completely. This is shown in informal conversations with PLWHA who are included neither in the public nor in the private health systems and therefore have to rely on the black market to buy medication.

On the other hand, non-profit organizations like the Laura Rodriguez Foundation or the Savia Foundation, which used to get drugs from international cooperation organizations are no longer involved in this task. That is because of the universal delivery of drugs to all people included in both the public and private health systems.

Nevertheless, there are people who do not want to be involved with the national health systems and therefore resort to clandestine drug sales due to discrimination or stigmatization. That is an alarming situation, since there are PLWHA who do not take drugs so they can afford a living.
C) THE RIGHT TO INFORMATION

Treatment

It’s important to point out that the staff at the primary healthcare centers has been trained by the CONASIDA in the context of a GF project in Chile. They were trained by the primary and full care areas on delivering Elisa test results, which determine the presence of HIV in the blood. The interviewee says that in his case he was not given satisfactory information because the person in charge of delivering results at the hospital left him at a loss, with little information on HIV/AIDS:

“At the hospital they tried… I think that was her way of talking to me, giving me advice, I don’t know, but I was so… I am strong, have lots of guts and didn’t… but she seemed a little lost herself, disconnected with the whole issue, and when I started treatment, nothing… I didn’t need it, it was very positive, they… the nurses told me there was this group, but I’d never needed anything like that, I personally never needed it, the trauma was, say, clear, like you know of friends who are on the medication and had strange dreams and didn’t do so well. And the process of adaptation to the drugs, I was a bit scared of it, but I had the support of a boyfriend I have in France and he was very important, I was no longer afraid and believed it, so I didn’t need… I didn’t get any psychological troubles or anything, I believed it, the first day I even had a beautiful dream and then nothing else, so no… The pills don’t cause me problems, they haven’t done me any harm, it was not violent… all has been extremely positive and normal, natural, great.”

While counseling is the best public policy to privacy in that it protects confidentiality, it was only legally protected starting from 2005 (AIDS Law). Nonetheless, confidentiality has been contemplated in the full healthcare model since the 1990’s. Non-discrimination is not only part of the law, but also of the full care model for primary attention and the committee’s ethical principles. The education that should be included by the counseling process did not have adequate staff in this case.
D) THE RIGHT TO PRIVACY

Current treatment

In this case, privacy was violated because there were no material conditions for an appropriate intervention. The delivery of drugs exposes HIV patients to the public eye:

“I’ll never forget it. Yes, I forgot it 2 or 3 times the first month, but never again since then, never again. I take them every day at 10 at night and in the morning, except when the doctor told me it was not necessary to be there at 8... I can spend one hour, I know, I can take it really easy because it was like an important part of agreeing to it, making it a habit, you know... that was the thing, I was aware I had to do it and I am a very disciplined guy.”

Regarding the place where antiretroviral drugs are delivered, the interviewee says there is a special window to retrieve the medication. He says that it is a space for people with “special diseases” and that considering the right to confidentiality guaranteed by the AIDS Law it is rather stigmatizing not only for himself but also for all those who have to go to the window for drugs. This, however, does not bother the interviewee since he believes delivery is swift.

“At the pharmacy... there is a pharmacy for, I don’t know, special people, for some diseases that are as less public, so there I am, there is one that is right on this tremendous windows. There are two of these where people can go to, but I don’t find it a problem to be on line because they work fast, they are very efficient.”

As for registering with the care protocol for PLWHA, the interviewee says the process was complicated because he didn’t want to be there but had to due to the bureaucracy of the public health system. He had to wait in line for a long time besides facing other difficulties:

“I was simply going to do everything I was supposed to. I had to do it efficiently so I could join the program, so I had to have lots of patience. There were times I had to wait a lot, wait in a lot of lines, wait for, I don’t know, for them to give our the cards or make an appointment or understand the mechanism and... but all that didn’t matter because I hoped to live, I didn’t care if I had to... sometimes it did get to me to wait so long, but it soon went away.”

He also says he had to wait to be seen just as long as any other patient. Medical appointments in the public system are usually scheduled for 9 am, but patients are not seen until 11 am. This creates bottlenecks and makes people unhappy.

“The doctor won’t see you at 9. If you’re scheduled at 9, they’ll see you at 11. Sometimes you have to wait for up to 3 hours for Ballestero, but that is all.”
Concerning the right to health, one of the most significant differences is provided by the Aids Law 19,779, as an effort of civil society organizations, PLHIV, members of parliament and government for health protection of HIV/AIDS. The contrast between the two cases shows progresses and obstacles. As far as treatment is concerned, efficiency and adhesion are highlighted by comparing the interviews in universal access. Implementation of the full healthcare model seems to fail in counseling after the test and in waiting times, but those are no different for the general population. An interesting aspect is the cultural discrimination in case 2, which refers to the necessity of anonymity in a rural area.

The fact that drugs are free is highly valued.

Differences in PLWHA perception regarding access to antiretroviral treatment has varied according to the social and political contexts. Nevertheless, discrimination persists in different areas (rural zones in this case).

It’s interesting to see that “users” are empowered. The perception of chronic infection has shifted the symbolic position from objects of observation to observers.

The difficulties faced by PLWHA in accessing healthcare are no different from those faced by the population in general.

It is important to consider the emergence of the black market - and its consequences - when the state does not guarantee the health of the population.

Chile, through its Ministry of Health, meets high international standards related to health care to PLWHA. This somehow ensures fulfillment of the right to health, which is currently granted by both the private and public health systems. Nevertheless, the reports account for stigmatization and discrimination against PLWHA when these have to rely on public health services. This situation generates lack of reports and consequently limits access to ART.

The cases studied highly value the right to information. This is strengthened by three factors. First, the support of the organized PLWHA population, who made the first collective interventions for self-care and adhesion to ART. Then, the design and implementation of public policies according to the national reality. Finally, the support of the Global Fund, which made it possible to train healthcare workers in both counseling and care.

On the right to non-discrimination, there have been changes in the relationship established between healthcare providers and users. These changes have been supported by public policies like the model of full care to PLWHA. Nonetheless, when PLWHA need to be referred to experts in the public health system, they are not only discriminated against and stigmatized but are also the last in line. The main argument is that prophylaxis requires medical instruments.