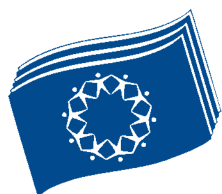
In-country monitoring of the implementation of the Declaration of Commitment adopted at the UN General Assembly Special Session on HIV/AIDS

A Four Country Pilot Study



June 2004 • International Council of AIDS Service Organizations (ICASO)

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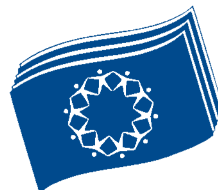

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ABBREVIATIONS

ART	Antiretroviral Therapy
ARV	Antiretroviral
ASO	AIDS Service Organization
CBO	Community Based Organization
CCM	Country Coordinating Mechanism
CSO	Civil Society Organization
DoC	Declaration of Commitment
HAART	Highly Active Antiretroviral Therapy
HIV+	HIV Positive
IEC	Information Education Communication
IDU	Injecting Drug User
MSM	Men who have Sex with Men
M&E	Monitoring and Evaluation
MoH	Ministry of Health
NAP	National AIDS Program
NGO	Non Governmental Organization
PLWHA	Persons Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session (on HIV/AIDS)

DEFINITIONS

CIVIL SOCIETY: This term may include the following groups: Persons Living with HIV/AIDS (PLWHA) and their networks, AIDS Service Organizations (ASOs), caregivers, Community Based Organizations (CBOs) and Non Governmental Organizations (NGOs) working in areas of AIDS, sexual health, youth, and/or with vulnerable groups, faith based organizations, media, medical associations, donors and private sector businesses.

COMBINATION THERAPY: Any two or more drugs taken together. In the context of antiretroviral (ARV) therapy, this term is used to refer to the necessary use of more than one ARV in a given treatment regimen. The rational behind this strategy is to prevent the emergence of drug-resistant HIV virus, which occurs more rapidly when treatment consists of solely one drug (mono therapy). The gold standard in ARV therapy is HAART (highly active antiretroviral therapy), which usually consists of a combination therapy of three separate ARV drugs.

GENERIC DRUGS: Generic medicines are pharmaceuticals promoted and marketed using chemical names rather than brand names. They are usually produced by companies other than the brand name patent holder. These drugs are sold at considerably lower prices than brand name medicines both because they are not saddled with the enormous costs of research and development (borne by the patent holder) and because, in the absence of a monopoly held by the brand name producer, generic market competition creates substantial downward pressure on prices. In most instances, the generic version of a drug is identical to its brand name equivalent.

MULTIPLE HEALTH PACKAGE: This should include the following: gynecological facilities for women that ensure periodic check-ups; initial counseling services; diagnosis and post diagnosis; counseling/information sharing on treatment and post-treatment care; treatment; follow up check ups; and care and support services.

NATIONAL AIDS PROGRAM (NAP): A government-run and regulated program aimed at addressing the HIV/AIDS epidemic across all sectors of society and undertaken on a national scale.

EXECUTIVE SUMMARY

ICASO undertook a community based research project to assess civil society participation in the implementation and monitoring processes of the Declaration of Commitment (DoC) adopted at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001. It was expected that this pilot project would strengthen the capacity of civil society in monitoring and evaluating national progress in achieving the targets outlined in the DoC. At the same time the project would facilitate the forging of constructive working relationships between governments and civil society. This research project was designed as a four-country pilot study. The final results from the study will be used to scale up the project to include up to 20 countries in 2004 and 2005.

The first stage of the project design was a selection of a sampling of countries. Four countries: Kenya, Philippines, Ukraine and Venezuela representing the four regions of the world (Africa, Asia, Europe and the Americas) were selected for the study following consultation with ICASO's Regional Secretariats and UNAIDS. Five commitments: access to treatment, empowerment of women, human rights of persons living with HIV/AIDS (PLWHA) and other vulnerable groups, resource allocation and civil society involvement were selected for the study. These were selected because they are examples of areas where government response has been weak and civil society participation and involvement has been strong. The research team at ICASO provided guidelines and research tools to assist the in-country researchers in their data collection process. ICASO developed a simple set of tools as the indicators developed by UNAIDS were felt to be too complex for use by civil society. Also it was felt that the UNAIDS indicators were not helpful to get an accurate picture of the actual implementation of the commitments and the people benefiting from the DoC.

Research at the country level involved collection of primary data from NGOs, CBOs, ASOs, representatives of PLWHA and vulnerable groups, government officials from relevant ministries and from private companies. Secondary data sources included government policy and legislative documents, national progress reports on HIV/AIDS, research reports, journals, web site materials and other relevant documents. The overall report is based on the information provided in the national reports from the four countries.

RESULTS FROM THE RESEARCH

Access to Treatment: It is difficult to assess whether or not the adoption of the DoC has had any influence on governments' decisions to scale up ARV distribution and access. Nevertheless, in the last five years, there has been significant improvement in most countries (and the four countries in this pilot study demonstrate that) at least at the policy level to guarantee access to treatment. Implemention of many of these policies is yet to be realized. Some positive steps have been taken towards a lowering in the prices of ARVs and the importation of generics. However, drug and treatment costs are still high and their availability is confined to major urban centers. Further, there is poor information dissemination on the part of the government and many PLWHA continue to be treatment-illiterate. NGOs and CBOs in all four countries have played a critical role in assisting PLWHA to access medicines and treatment. The study also highlighted that in most cases where there is little community organizing or advocacy for access to ARVs, PLWHA are denied a critical resource.

Empowerment of Women: The four-country study indicated that the adoption of the DoC has had no impact in reducing the vulnerability of women to HIV/AIDS. This has been one of the most neglected areas in terms of governments' response to the AIDS epidemic. Also, civil society initiatives towards fulfilling this commitment in the four countries have been limited and this has fuelled infection rates among women. Today, fifty percent of those infected globally are women. To stem the tide of the epidemic, the magnitude of this problem must be recognized and critical steps must be taken by governments and civil society towards empowering women.

Human Rights of PLWHA and other Vulnerable Groups: From the in-country study, it is difficult to assess if the initiatives taken by governments have been due to the DoC. However, what is clear is that three years after the adoption of the DoC, PLWHA and other vulnerable groups continue to face stigma and discrimination that hinder their access to HIV/AIDS related services. Although some legislation has been adopted, these have not impacted on the existing realities; human rights of PLWHA and other vulnerable groups continue to be violated, whether this be related to confidentiality of HIV status or loss of employment or access to medications. Governments in most cases have failed to meet their international obligations as outlined in the various treaties and conventions when it comes to respecting, protecting and fulfilling the human rights of PLWHA and vulnerable groups as they continue to be marginalized and discriminated against in the provision of all HIV/AIDS related services.

Resource Allocation: Adequate resources are critical for responding to the AIDS pandemic at the national level. This was recognized in the DoC and all governments made the commitment to increase and prioritize national budgetary allocations for HIV/AIDS programs. However, the study brought into sharp focus the resource gaps that exist at the country level for addressing issues related to HIV/AIDS. Unfortunately, none of the four governments have increased their health allocations when compared to the overall budget. In some cases the allocation has even been reduced as other developmental issues get greater priority. This is particularly significant especially since without adequate financial resources, none of the other commitments can be fulfilled.

Civil Society Involvement: Civil society organizations have been in the vanguard of the movement to curb HIV/AIDS and a critical force in preventive education, advocacy for access to ARVs and the provision of direct services in treatment, care and support for the infected and affected. They complement and strengthen the work of government departments and many of them are building partnerships with private sector organizations and agencies to ensure that health and social services reach those most vulnerable, marginalized and excluded. NGOs and CBOs have lead the way in demanding the full realization of the human rights of PLWHA and other vulnerable groups. These rights include high standards of health care, access to other factors of survival, and to be free from stigma and discrimination.[1] However, in spite of their active role since the early days of the epidemic, their involvement in government decision-making processes has been of a symbolic nature. In none of the countries that ICASO studied has civil society been involved in any meaningful way to implement or monitor progress on the DoC. This raises a crucial question: why is civil society not involved in developing AIDS policies apart from the token representation on some national AIDS bodies and in monitoring or measuring progress made in meeting the DoC targets?

[1] The NGO Community, a Leader or Follower in the HIV/AIDS Response (draft paper), ICASO, 2004

RECOMMENDATIONS

What became clear from the research study was that despite some legislative measures as well as programmatic approaches, there is no evidence to indicate that the governments' efforts have been due to the adoption of the DoC. Further, often policies are adopted but seldom implemented. In most cases governments continue to lack political will and interest, adopting policies as a matter of routine. In other cases, they simply lack the financial resources to implement those policies. Thus, civil society has a crucial role to play in ensuring that what exists at the policy level also reaches the populations in need of those services. In order to better implement the commitments in the DoC, ICASO recommends the following strategies:

Partnerships between Government and Civil Society: Governments must engage NGOs and CBOs in national and local decision-making processes and not merely provide for a token presence on different governmental bodies. Further, governments must forge effective partnerships with civil society for the design and implementation of policies and programs for fulfilling the commitment in the DoC. Similarly, civil society too has an obligation to identify opportunities to participate and contribute to the formulation of government policies and equip themselves to effectively present and discuss their issues and agendas.

Monitoring & Evaluation Task Force: Governments should set up a national monitoring and evaluation task force with adequate representation from civil society to evaluate the implementation of the policies and programs adopted by the government in line with the DoC. One of the responsibilities of the task force would be to ensure that funds allocated are channeled for the right use.

Training and Capacity Building: Governments and civil society must engage in better dissemination of information related to the DoC, including its monitoring and evaluation. This can be done through capacity building and training programs for all those playing a role in policy and decision-making on HIV/AIDS. Further, organizations such as UNAIDS and ICASO must engage national NGOs and CBOs to enhance their M&E capacities so that they are better equipped to monitor the implementation of the DoC and advocate for the fulfillment of the commitments.

Review of the Indicators: UNAIDS must revisit and review its indicators for monitoring the implementation of the DoC to measure government progress. One of the major learning from this project was the realization that the indicators developed by UNAIDS do not measure implementation of policies but simply measure their adoption. Consequently, UNAIDS must consider developing new indicators with civil society inputs that allow civil society to report on governments' progress in implementing the DoC. Also, these indicators should be more relevant to the country's situation so that they can be of greater use in program planning and policy formulation.

INTRODUCTION

Declaration of Commitment

In June 2001, Heads of States and Representatives of Governments met at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS). This meeting was a historic landmark, reflecting the fact that, in 20 years, the HIV/AIDS pandemic has caused suffering and death worldwide beyond belief, destroying entire communities, reversing development gains, and posing a serious threat to the population. At this meeting, Heads of States and Representatives of Governments adopted the Declaration of Commitment (DoC) on HIV/AIDS.

"For there to be any hope of success in the fight against HIV/AIDS, the world must join together in a great global alliance. The Declaration of Commitment on HIV/AIDS is the culmination of a year long process of awareness, engagement and mobilization. My great hope is that it signals the emergence of a response to this deadly disease - by Governments, multilateral organizations, the private sector and civil society - that could soon match the scale of the epidemic itself."
- Kofi Annan, United Nations Secretary-General

The DoC on HIV/AIDS is an important document because it reflects political will at the highest levels of political power. It is not a binding document, but it states what governments have pledged to do – themselves, with others in international and regional partnerships, and with the support of civil society - to reverse the epidemic. It sets real targets for accessing prevention, care, treatment and support, empowering women, protecting human rights of persons living with HIV/AIDS (PLWHA) and other vulnerable groups and increasing resource allocation among others and strategies to do it. The DoC is a powerful tool to guide action, commitment, support and resources for all those fighting the epidemic at all levels.

Implementation of the DoC is a government-led process that must include active civil society involvement. The governments of the world have made an unprecedented commitment. They have issued a collective statement detailing a strategy for addressing HIV/AIDS and reversing the epidemic, a strategy with clear goals and timelines.

For measuring and monitoring progress achieved towards implementing the DoC, UNAIDS[2] developed a set of core indicators in 2002. These indicators were meant to facilitate the review process and to help governments report on their progress in meeting the goals and targets set out in the DoC. UNAIDS also developed guidelines to provide countries with technical guidance on the indicators (specifications, information required and interpretation).[3] (See Table 1).

In 2003, national governments used these indicators to submit their reports to UNAIDS on the

[2] Joint United Nations Program on HIV/AIDS

[3] The principal measurement tools required to provide the necessary data are nationally representative, population-based sample surveys; schools, health facility and employer surveys; and specially designed targeted surveys of marginalized groups. Other data requirements should be met from existing routine programme monitoring sources. It is envisaged that these will typically include education and health service records as well as specific HIV/AIDS or sexually transmitted infections (STIs) control programme and surveillance records. (Source: UNAIDS Guidelines on the Construction of the Indicators).

TABLE 1: Core indicators for implementation of the Declaration of Commitment

Global Level

INDICATORS	REPORTING SCHEDULE	METHOD OF DATA COLLECTION
Global commitment and action		
1. Amount of funds spent by international donors on HIV/AIDS in developing countries and countries in transition	Annual	Survey on financial flows
2. Amount of public funds available for research and development of vaccines and microbicides	Annual	Survey on financial resource flows
3. Percentage of transnational companies that are present in developing countries and that have HIV/AIDS workplace policies and programmes	Annual	Desk review
4. Percentage of international organizations that have HIV/AIDS workplace policies and programmes	Annual	Desk review
5. Assessment of HIV/AIDS advocacy efforts	Annual	Qualitative desk assessment(s)

National Level

INDICATORS	REPORTING SCHEDULE	METHOD OF DATA COLLECTION
1. National commitment and action		
1. Amount of national funds spent by government on HIV/AIDS	Biennial	Survey on financial resource flows
2. National Composite Policy Index	Biennial	Country assessment questionnaire
2. National programme and behaviour		
1. Percentage of schools with teachers who have been trained in life-skills-based HIV/AIDS education and who taught it during the last academic year	Biennial	School-based survey and education programme review
2. Percentage of large enterprises/companies that have HIV/AIDS workplace policies and programmes	Biennial	Workplace survey
3. Percentage of patients with STIs at health care facilities who are appropriately diagnosed, treated and counseled	Biennial	Health facility survey
4. Percentage of HIV-infected pregnant women receiving a complete course of antiretroviral prophylaxis to reduce the risk of MTCT	Biennial	Programme monitoring and estimates
5. Percentage of people with advanced HIV infection receiving antiretroviral combination therapy	Biennial	Programme monitoring and estimates
6. Percentage of IDUs who have adopted behaviours that reduce transmission of HIV*	Biennial	Special survey
7. Percentage of young people aged 15-24 who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission **(Target: 90% by 2005; 95% by 2010)**	Every 4-5 years	Population-based survey
8. Percentage of young people aged 15-24 reporting the use of a condom during sexual intercourse with a non-regular sexual partner**	Every 4-5 years	Population-based survey
9. Ratio of current school attendance among orphans to that among non-orphans, aged 10-14**	Every 4-5 years	Population-based survey
3. Impact		
1. Percentage of young people aged 15-24 who are HIV-infected** **(Target: 25% in most affected countries by 2005; 25% reduction, globally, by 2010)**	Biennial	HIV sentinel surveillance
2. Percentage of HIV-infected infants born to HIV-infected mothers **(Target: 20% reduction by 2005; 50% reduction by 2010)**	Biennial	Estimate based on programme coverage

*Applicable to countries where injecting drug use is an established mode of HIV transmission
**Millennium Development Goal indicators
(Source: UNAIDS Monitoring the Declaration of Commitment on HIV/AIDS on the construction of core indicators, 2002)

progress made in implementing the DoC. These national reports[4] were used to monitor the progress made towards reaching the 2003 targets. The report of the Secretary General presented in September 2003 highlighted progress that had been made within and across regions, identified perceived gaps, provided guidance on ways to address those gaps, and emphasized strategies for the future. One of the conclusions of the report was that although most governments had developed and adopted national AIDS strategies, their implementation was very slow, mainly due to a lack of resources and technical capacity.

Although the responsibility to report on progress made in achieving the targets set out in the DoC is on governments, the DoC recognizes and calls for partnership among governments and civil society. Civil society input into the implementation and monitoring of the DoC is essential for transparency and accountability, as well as for gauging progress in actual benefit terms.

The Research Project

More than two years have elapsed since the DoC was adopted and yet the global AIDS pandemic shows no signs of abating. The 'AIDS epidemic update 2003' that was released by UNAIDS noted that the response to HIV/AIDS as measured by spending and political action has improved in recent years, but improvements are still far too small and slow in coming to adequately respond to the growing global epidemic. The devastating impact of the epidemic and its rapid spread means that national governments must work in partnership with civil society to find approaches to alleviating the impact of HIV/AIDS as quickly as possible.

Against such a backdrop, in 2003 ICASO undertook a research project to assess civil society participation in the implementation and monitoring processes of the DoC. It was expected that this pilot project would strengthen the capacity of civil society in monitoring national progress in achieving the targets outlined in the DoC. At the same time the project would facilitate the forging of constructive working relationships between governments and civil society actors. The final results should be used as a tool to advocate to governments for a greater role in monitoring of national progress towards implementing the targets outlined in the DoC.

Research Design and Methodology

This research project was designed as a four-country study, where each country can be seen as a case study on its own. The first stage of the project design was the selection of a sampling of countries. Four countries: Kenya, Philippines, Ukraine and Venezuela representing the four regions of the world (Africa, Asia, Europe and the Americas) were selected for the study following consultation with ICASO's Regional Secretariats and UNAIDS.

This was followed by a selection of specific commitments from the DoC for the research. A selection of commitments was necessary due to time and financial constraints. The five commitments that were selected are examples of areas where government response has been weak and civil society participation and involvement has been strong. ICASO wanted

[4] Country reports are available on the UNAIDS website at http://unaids.org/EN/other/functionalities/search.asp

to analyze the extent to which governments have fulfilled their obligations within the framework of the DoC and to examine the extent to which civil society has been involved in the implementation and monitoring processes of the DoC in these five areas.

The commitments that were selected were:

- Access to Treatment (DoC -paragraphs 15, 24, 26, 55)
- Empowerment of Women (DoC- paragraphs 14, 59, 60, 61)
- Human Rights of Persons Living with HIV/AIDS (PLWHA) and other Vulnerable Groups (DoC-paragraphs 13, 58, 96)
- Resource Allocation (DoC-paragraphs 9, 29, 82, 90)
- Civil Society Involvement in the Implementation of the DoC

ICASO thereafter identified and recruited researchers based in these four countries to implement this project.[5] The research team at ICASO provided guidelines and research tools to assist the researchers in their data collection process.[6] ICASO developed a simple set of tools as the indicators developed by UNAIDS were seen as too complex and not useful to get the kind of information that was being sought. Also it was felt that the UNAIDS indicators are not helpful in getting an accurate picture of the actual implementation of the commitments and the people benefiting from the DoC.

Research at the country level involved a collection of primary data. Primary data formed the core of the national study because it was felt that direct communication with the infected and affected respondents enables them to state their problems the way they experience them and also to suggest possible solutions. This took many forms including, identifying and sampling of key informants from relevant institutions and organizations as well as individuals from civil society. This included NGOs, CBOs, ASOs, representatives of PLWHA and other vulnerable groups, government officials from relevant ministries and private companies. Data was collected through questionnaires, focus group discussions and interviews. Some of these interviews were conducted in a more informal manner where the informant shared their experiences around issues identified in the DoC. Secondary data sources included government policy and legislative documents, national progress reports on HIV/AIDS, research reports, journals, UN reports, web site materials and other relevant documents. Some of the information collected come from informants who wanted to maintain their anonymity. For this reason, some of the data presented in this report does not have a formal reference to the source.

The findings were presented to ICASO in the form of a comprehensive national report that included individual experiences.[7] Each country report is unique as it takes into account the realities of that country and has its own national flavor. While some of the country reports (Kenya and Ukraine) have used more empirical data, those from Venezuela and Philippines are more anecdotal. The overall report tries to preserve the national experience of each

[5] see Appendix 1 for a list of in-country researchers and implementing agencies.

[6] see Appendix 3 for an example of Research Guidelines to Monitor Access to Treatment Commitment.

[7] These reports can be obtained by email requests to icaso@icaso.org.

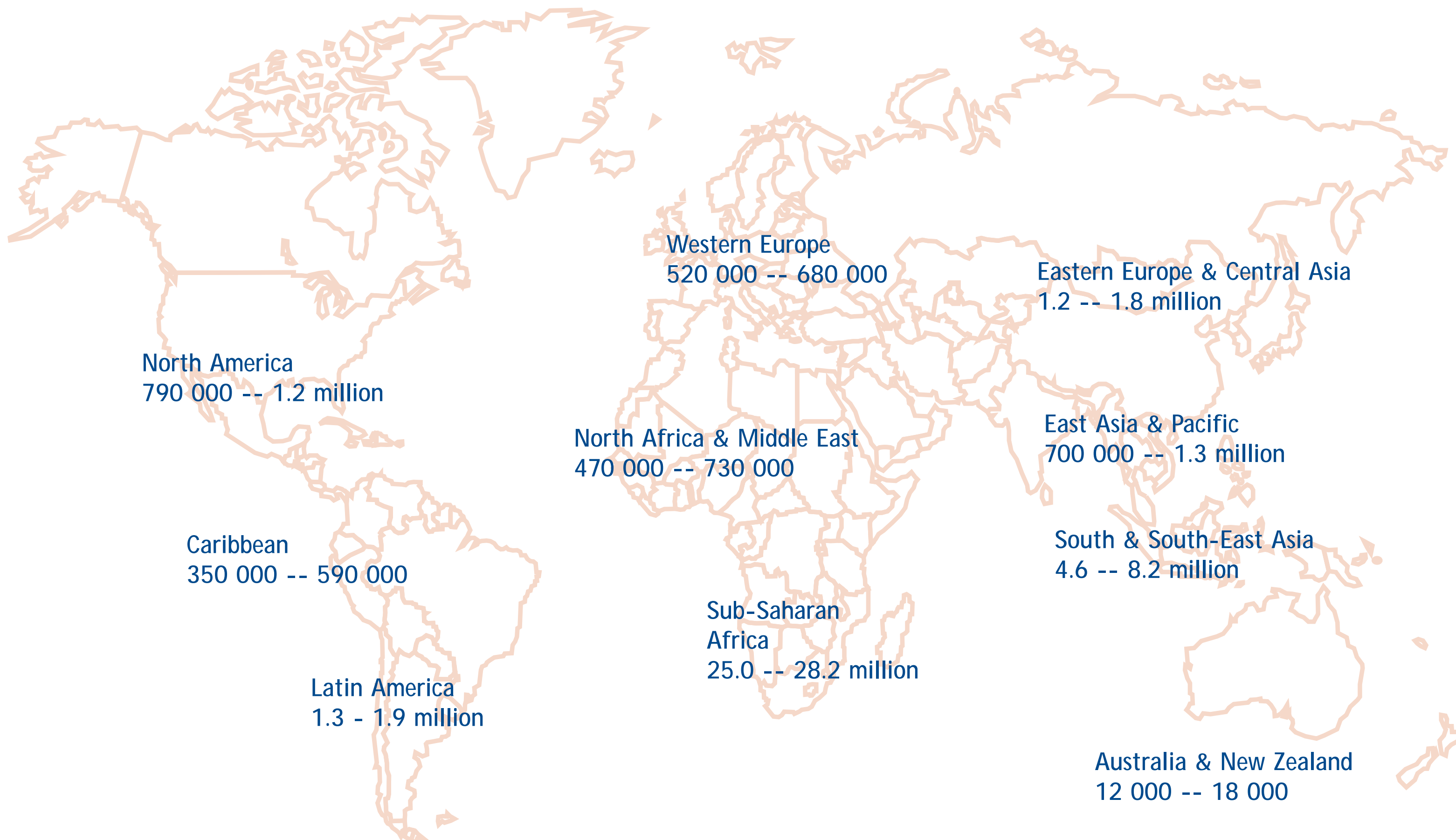
country and is therefore not confined to any strict narrative formula but rather tries to situate each commitment being evaluated within the socio cultural context of that country. Each commitment analysis is followed by some recommendations and lessons learned that cut across all countries.[8]

The final national reports were completed by January 2004. These reports were sent to the ICASO research team who then compiled, analyzed, interpreted and drew key lessons learned and recommendations for implementing the commitments and involving civil society in a meaningful way. This report was produced in June 2004. ICASO expects to roll out this project over the next two years.

[8] The information from the national reports in this overall report has been edited because of space constraints. All the country data and information are those provided by the in-country researchers and implementing agencies.

GLOBAL & REGIONAL HIV/AIDS SCENARIOS

Global & Regional Estimates of PLWHA, 2003



Total: 34 — 46 million

(Source: UNAIDS AIDS epidemic update, December 2003)

HIV/AIDS SCENARIO IN THE FOUR COUNTRIES

Kenya

Kenya has recently declared HIV/AIDS a national disaster. This was in recognition of the fact that over 2 million out of a total population of 29.5 million (2000) were infected with HIV and a cumulative number of 1.5 million people had died due to AIDS. Because of HIV/AIDS, life expectancy has dropped by approximately 13 years to 51 years (1998); while GDP reduced by -0.3 in 2000 and is expected to worsen in coming years. [9]

Philippines

According to official figures, there are 9,400 people living with HIV/AIDS out of a total population of 39.6 million.[10] The Philippines has an HIV/AIDS epidemic that has a huge potential for explosion fuelled by a large sex industry that exists throughout the country coupled with irregular and incorrect use of condoms. Further, many of the country's seven million migrant workers are vulnerable. The country is still trying to recover from a serious economic crisis and much of its scarce resources have been committed to other more urgent social and development priorities.[11]

Ukraine

Ukraine has the highest prevalence of HIV among the CIS[12] countries (an estimated 1 percent of adult population). There are an estimated 250,000 people living with HIV/AIDS out of a total population of 25.25 million.[13] The first HIV case was detected in 1987. Since 1995, infection rates have increased dramatically, mainly due to transmission among injecting drug users (IDUs). However, the proportion of sexually transmitted cases is significantly increasing from IDUs to their sexual partners.[14]

Venezuela

Venezuela has identified AIDS as one of its priority health problems. However the social and political upheaval during the last two years, the conditions of gender inequality, insufficient sexual education and social exclusion for people living with HIV/AIDS are some of the factors hindering prevention efforts.[15] Currently there are approximately 62,000 (exact numbers not available) adults (15-49 years) living with HIV/AIDS[16] out of a total population of 23.5 million.

[9] http://www.unaids.org/en/geographical+area/by+country/kenya.asp
[10] UNAIDS Report on the global HIV/AIDS epidemic 2002.
[11] http://www.unaids.org/en/geographical+area/by+country/philippines.asp
[12] Commonwealth of Independent States.
[13] UNAIDS Report on the global HIV/AIDS epidemic 2002.
[14] http://www.unaids.org/en/geographical+area/by+country/ukraine.asp
[15] http://www.unaids.org/en/geographical+area/by+country/venezuela.asp
[16] UNAIDS Report on the global HIV/AIDS epidemic 2002.

THE COMMITMENTS

Access to Treatment

There are over 40 million people living with HIV/AIDS (PLWHA) in the world and yet only a tiny fraction receives life sustaining antiretroviral (ARV) treatment or therapy.[17] According to current World Health Organization's (WHO) estimates approximately six million people infected with HIV in the developing world need ARVs to survive. Only 300,000 have access to it, which means that an estimated five percent of those in need are accessing them. The failure to deliver ARVs to the millions of people who need them is a global health emergency. Access to care, treatment and support is thus a central focus of HIV/AIDS advocacy efforts. The WHO in 2003 unveiled its '3 by 5' Initiative whereby it has committed itself to providing ARVs to three million people by 2005. This initiative can be seen as a step towards achieving the access to treatment targets of the DoC.

The elevated cost of treatment impedes access for more than 90 percent of the population living with HIV/AIDS. This renders health as the privilege of the few rather than the right that it is. However, barriers to access take many forms, apart from the cost of drugs. This includes political denial and disinterest at all levels, stigma and discrimination, and inadequate health systems. ICASO therefore felt that this commitment must be a priority for all national governments, especially since access to treatment has a direct impact on reducing the mortality and morbidity associated with AIDS by allowing PLWHA to live healthy and productive lives.

The research study in the four countries showed that while some governments

Access to Treatment Commitments[18]

"We heads of State and Governments and representatives of States and Governments….."

DoC paragraph 15: Recognize that access to medication is a fundamental element for achieving progressively the right of everyone to the highest possible standard of physical and mental health;

DoC paragraph 24: Recognize that the availability and affordability of drugs and related technology should be reviewed, and the costs of such drugs and technology reduced in collaboration with the private sector and pharmaceutical companies;

DoC paragraph 25: Recognize that the lack of affordable drugs, a feasible drug supply and adequate health systems is hindering an effective response to HIV/AIDS, especially for the poorest people;

DoC paragraph 26: Recognize that countries should increase access to drugs through innovation and domestic industries consistent with international law, and the impact of international trade agreements on access to drugs should be further evaluated;

DoC paragraph 55: Commit, by 2003, to develop strategies, in collaboration with the international community, civil society and the business sector, to strengthen health care systems and address factors affecting access to drugs, e.g. affordability, pricing, and system capacity. Urgently, make every effort to provide the highest attainable standard of treatment of HIV/AIDS, including prevention, treatment for opportunistic infections, and ARV therapy. Cooperate in strengthening pharmaceutical policies to promote innovation and the development of domestic industries consistent with international law.

[17] UNAIDS AIDS epidemic update, December 2003.

[18] Adapted from the DoC

have taken steps towards implementing the targets outlined in the DoC, more needs to be done. The cost of ARVs, treatment for opportunistic infections, and of laboratory tests together with the lack of a proper health infrastructure continues to be a major barrier.

In Kenya, ARV treatment in public hospitals is at a subsidized cost of US $20 per month; however, this is only available in some urban centers. In the Philippines, HIV/AIDS is not a priority for the government. They have made no effort to secure funding to distribute ARVs free of charge. As a response, NGOs have taken a leadership role in advocating for the importation of generic drugs, which has led to dramatic price reductions. In Ukraine, in keeping with the targets of the DoC, the government has adopted legislation to provide treatment free of charge in public hospitals. However, only three percent of people in need of ARVs have access to it. The situation is somewhat similar to Venezuela, which already had policies and programs even prior to the adoption of the DoC on providing ARVs free of charge to those who need them. However, due to the high cost of medicines in general and of ARVs in particular, and the present economic situation in the country, only a limited number of PLWHA now have access to them.

Kenya

Initiatives taken by the Government

Currently, there are 220,000 PLWHA in Kenya in need of ARVs but only 12,000 are receiving those drugs.[19] Access to medication and care has been included in the Kenyan National Strategic Plan as a priority. Around Ksh 2,700 million [20] (approx. US $34 million) was budgeted in the plan for 2000-2005, although, in the 2002-03 financial budget, the government allocated only Ksh100 million [21] (approx US $1 million). It is clear that the government has not met its own targets in spite of what exists in the Strategic Plan. The National Strategic Plan establishes a detailed plan for treatment for the infected and support for the affected. However, a lack of resources or any shortfall will definitely have a negative impact on the implementation of those policies.

The DoC (paragraph 24) states that the availability and affordability of drugs and related technology should be reviewed and the costs of such drugs and technology reduced in collaboration with the private sector and pharmaceutical companies. In accordance with this aspect, a number of measures have been taken by the government of Kenya. Following prolonged international and national negotiations with pharmaceutical companies some progress has been made towards the reduction of ARV prices. Also, Kenya has taken steps to provide ARVs in public hospitals. The Ministry of Health (MoH) has awarded tenders for the supply of medicines to various pharmaceutical companies and generic ARV manufacturers.[22] The government has so far registered 20 pharmaceutical companies that are willing to supply the country with over 60 ARVs for the recently launched National HIV/AIDS Treatment Campaign.[23] In cases of parallel importation, the government has also installed several new drug quality maintenance machines at the National Drug Quality Control laboratories to ensure that the drugs imported are of required efficacy.

Kenya will start ARV treatment at 28 centers around the country. Initially 3,000 people will be treated at public hospitals at a subsidized cost of US $20 per month. The government will gradually raise the number of people on the treatment program to 20,000 over the next two years. The Ministry of Health will take the lead in this scale up of activities and ensure that affordable quality ARV drugs are accessible to all Kenyans in the near future.[24] Further, recent legislative amendments have been aimed at enhancing ARV access to a wider number of PLWHA. The dramatic price reductions witnessed recently also offers hope that ARVs will soon be available to other parts of the country and not just at major urban centers. Through some of these measures, the government, in the last eleven months, has managed to reduce AIDS related deaths from 700 to 300 a day.[25] In order to scale up ARV therapy country-wide, the government and other stakeholders realized the need for a simple guide on ARV regimens. The regimens proposed were deliberated upon in several meetings by members of the ARV task force comprising of diverse stakeholders from civil society in addition to government representatives.

According to Médecins Sans Frontières (MSF), the average cost of the cheapest generic ARV is around US $300 per patient per year which is similar to the government's estimates. However, this needs to be seen against the fact that an estimated 56 percent of Kenyans earn US $1 per day (approx US $350 per year).

[19] Kenya Coalition for Access to Essential Medicines, Chairman's report in the Kenyan newspaper Daily Nation, September 24, 2003.

[20] Kenyan Shilling (exchange rate to US$ is approx. 78 Kenyan shilling per 1US$).

[21] Kenya National HIV/AIDS Strategic Plan 2000-2005.

[22] Local Daily, East African Standard, October 6, 2003, page 6.

[23] Source: Chief Chemist, Dr. Kipkerich's report in the People Daily, October 4, 2003, page 5.

[24] Source: Dr. Chebet, National AIDS and STIs Control Program.

[25] National AIDS Control Council Director's Speech in the Daily Nation, December 18, 2003, page 7.

Civil Society Response

A large number of NGOs are involved in care and treatment programs. The African Medical Research Foundation (AMREF) has care programs for PLWHA in slum areas. The foundation is taking care of 50 AIDS patients by offering them ARV drugs through the AMREF Treatment Scheme.

To address the need for a simplified and standardized approach to treatment, the Ministry of Health, several NGOs, AMREF and the US Center for Disease Control and Prevention have begun a collaborative program to deliver comprehensive HIV/AIDS care, including ARV therapy, to approximately 300 adults living in Kibera slum, Nairobi. Program participants are offered social services, screening and treatment for active TB, preventive therapy for TB, and prophylaxis for opportunistic infections.

KICOSHEP, an NGO in Kenya started counseling and testing services in 2001 in five centers in Nairobi. This initiative was a response to a need from the community to enable community members to know their status early enough so as to help in treatment access for those who were positive as well as providing counseling on prevention to those who were negative. The five centers are recording a daily attendance rate of 12-15 persons in each center.

Barriers and Challenges

Kenya faces a number of barriers in scaling up access to treatment. The quality of health care has worsened with the increase in the number of HIV/AIDS patients and the government has had to grapple with its budgetary allocations. Access to treatment is denied to the majority of PLWHA due to the high cost of drugs and tests as well as lack of good infrastructure for the provision of ARVs. Further, treatment is restricted to major hospitals and big urban health institutions, which also restrict access. Finally, there is a failure to implement many of the plans that have been developed to expand access; there are national plans, councils and programs but the reality is that most people still have no idea how to get affordable treatment for HIV infection.

Philippines

Initiatives taken by the Government

Since the 1990s the Philippine National Drug Policy has been working towards rationalizing drug production, procurement, distribution and use through the essential drugs concept. Very recently following the advocacy efforts of several NGOs, some generic ARVs were included in the Essential Drug List. This however, does not seem to have been a result of the DoC alone.

With regard to improving and expanding access to drugs and related technology as outlined in the DoC, very little initiative has been taken by the government. Access to drugs is limited to a few PLWHA as the cost of drugs and of treatment continues to be very high. The importation of cheap generic drugs has been allowed following the advocacy efforts of some non-governmental agencies working in the area of HIV/AIDS. Positive Action Foundation Philippines Inc (PAFPI), for instance, has been allowed to import generic ARVs from CIPLA, an Indian pharmaceutical company. Monthly treatment based on generic medicines can cost a patient about US $50 while treatment based on branded drugs cost approximately US $700 per month.[26] Based on recent estimates, the cost of viral load testing is between PhP[27] 7,000-10,000 (approximately US $126-$180).[28]

Though the DoC explicitly states the need for developing policies for widening access, there is no policy yet to distribute these drugs to all those in need of treatment. Besides, the government does not have the resources to distribute ARVs free of charge. It needs to be emphasized that in spite of the commitments in the Declaration, health is not a priority for the national government as apparent by the budget allocations. During the last ten years, the annual health budget has never exceeded 3.5 percent of the total budget and this scenario has not changed even after the DoC was adopted. Unfortunately, the government's resources are already committed to programs that are deemed more important. HIV/AIDS is not a high priority for the government. Also, the Philippine National AIDS Council (PNAC), which is the government's arm tasked to consolidate and propose actions related to HIV/AIDS is not inclined to use its limited resources to improve access to treatment.

> *"Access to antiretroviral therapy in the Philippines is limited because of the prohibitive cost of branded drugs. HIV/AIDS support groups and civil society organizations working with PHAs have spearheaded current efforts to make the drugs more accessible to PHAs. Generic drugs produced by other Asian countries are less costly, but are difficult to access because of drug importation policies. If the importation of generic drugs will be facilitated, it is expected that the number of PHAs taking antiretroviral therapy will increase."*
> *– Philippines Progress Report to UNAIDS*

Civil Society Response

It must be emphasized that for most PLWHA, access to ARVs cannot be found within the government health systems but rather within the NGO sector, through organizations such as PAFPI, PINOY Plus and the Remedios AIDS Foundation among others. Nevertheless, there are challenges here too.

[26] AIDS Research Group, Department of Health Research Institute of Tropical Medicine.
[27] Philippine Peso (exchange rate to US$ is approx. 56 Philippine peso per 1US$).
[28] AIDS Research Group, Department of Health Research Institute of Tropical Medicine.

PAFPI's program for 'access to treatment' is a response to the inaction of the Philippines government. PAFPI realized that providing treatment does not have to be very expensive. Hence, it chose generic ARVs to be able to serve more persons. To get into the program, a PLWHA has to get a referral or prescription from a government hospital. This prescription then has to be presented to PAFPI who thereafter provide the medication. Not everyone however is eligible to join the program. A CD4 count of 200 or below is required to get in. Currently there are 32 individuals on this treatment program.

These organizations require PLWHA to volunteer their time at the office. PLWHA, however, complain that this scheme of doing voluntary work in exchange for free medication can be disadvantageous to those who have not yet come out with their HIV status. As such, though this program has helped avail themselves of treatment, they believe that it is discriminatory.

While access to treatment has been made available by some NGOs by procuring generic drugs, sustaining these programs require resources that NGOs severely lack. It is largely through the generosity of international agencies that these programs continue. This should be the responsibility of the government, as it is their duty to ensure the right to health of all inhabitants. NGOs have been at the forefront in demanding that government provide for the needs of PLWHA. With the support and assistance of NGOs, people infected and affected by HIV/AIDS have been able to demand and secure financial and other support from the Social Security Service, the Overseas Workers' Welfare Administration and the Department of Health.

Barriers and Challenges

The major barrier to accessing treatment is economic. It is therefore imperative that policies and appropriate legislation be implemented to ensure that PLWHA have access to cheap and affordable treatment. Further, PLWHA living outside Manila are at a disadvantage as the centralized character of ARV delivery often causes delays, which can hamper the treatment regimen of PLWHA living outside the capital city. Above all, for the Phillipine government, AIDS is not a priority as indicated in their budgetary allocations.

Ukraine

Initiatives taken by the Government

In November 2001, the Cabinet of Ministers approved the national list of main (life-supporting) drugs and medical supplies. ARVs were included in that list. However there are no indications that this was a result of the DoC. Although this list is based on the WHO recommendations, most doctors and pharmacists are not aware of it since it has not been widely disseminated. Though the essential drug list exists, there are no measures for its implementation and/or legislation to support supply and improving access to the drugs listed.

Some measures to scale up access to treatment have been taken. These include the procurement of ARVs from the state budget and their free distribution. Further, the government's negotiations with international pharmaceutical companies led to an agreement by which prices of ARVs went down by as much as 70 percent to US $1,700 per year per person. These prices will remain in force until 2007. Generic drugs are allowed for use only if they comply with registration procedures established by the Ministry of Health. An annual supply of these drugs cost approximately, 1000.00 UAH[29] (approx US $187.65).

To some extent, the adoption of the DoC has helped the enactment of legislations to expand access. In 2002 ARVs were available to 55 PLWHA out of the 6000 who needed them, as per expert estimates. As of August 2003, 200 people including 19 children benefited from ARV therapy (three percent of people in need of it). ARV therapy is also provided free of charge within the framework of the program Prevention of Mother to Child Transmission as a result of a Decree of the Ministry of Health.

"When faced by the threat of disruption of treatment for those who had been on therapy, the All Ukrainian Network of PLWHA started a mass campaign to provide medications to people in need of it. A part of the expenses were thereafter covered by the state and the other part was provided by international organizations, thus the therapy was not interrupted due to the advocacy efforts of the Network."

– The All-Ukrainian Network of PLWHA Representative.

The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) has allocated funds for Ukraine to procure ARV drugs. According to the project implementation plan developed by the MoH, with this grant 4000 people in Ukraine should have received ARVs in 2003. As of December 2003, the needed medications had not yet arrived in Ukraine.

Civil Society Response

A number of NGOs have initiated discussions with the government to increase access to ARV therapy. For example, Médecins Sans Frontières (MSF) has advocated for the use of quality generic medications for HIV treatment in Ukraine. These efforts have led to the allocation of funds for testing generic drugs for their quality and suitability. Further, the All-Ukrainian Network of PLWHA and MSF have been advocating for domestic production of

[29] Ukraine Hryvnia (exchange rate to US$ is approx. 5.33 UAH per 1 US$).

generics in Ukraine. This has led the President of Ukraine to issue a decree on the possibility of domestic manufacture of ARV medications.

While availability of ARVs has expanded, information about ARVs tailored to the needs of PLWHA is still scarce and has only been developed by some NGOs. Information materials on ARVs have been developed and disseminated by some NGOs, such as the International HIV/AIDS Alliance and MSF who published a series of brochures titled 'Series for Positive People'.

Barriers and Challenges

A key obstacle to access to treatment is the medical service delivery system itself. On a policy level, the state guarantees to provide necessary drugs to PLWHA free of charge and is currently the main, if not the sole, procurer of ARV drugs. However, due to a lack of resources, free ARVs cannot be supplied to even to those who need them urgently. Private insurance schemes for medical coverage are underdeveloped in Ukraine and hence given the existing situation, the majority of PLWHA cannot afford treatment at their own expense due to the high costs of drugs and tests.

Venezuela

Initiatives taken by the Government

Venezuela already had policies and public health programs that included the provision of ARVs, medication to treat opportunistic infections and diagnostic tests free of charge prior to the adoption of the DoC. According to officials from the Ministry of Health and Social Development (MHSD) and the Venezuelan Social Security Institute (IVSS), as well as PLWHA activists interviewed for this study, these programs are still in place and the adoption of the DoC has not had any impact on the access to treatment situation.

According to the 2003 HIV/AIDS National Strategic Plan, 13,000 PLWHA had access to ARVs through the government, private institutions and NGO programs. The public health system supplies 17 different ARVs. Diagnostic, control and follow-up tests, related to HIV/AIDS and opportunistic infections are carried out in the national laboratory network. However, in 2002 and 2003, these tests were not carried out in public labs due to a lack of financial resources.

Civil Society Response

Given the inaction of the Government and the lack of implementation of policies and programs, NGOs working on HIV/AIDS started programs to provide access to treatment. These services are provided by trained professionals and counselors (most of them PLWHA themselves). Also NGOs have been actively advocating to the government to fulfill their commitment to provide ARVs free of charge and recognize access to treatment as a human right.

> During 2003, ACCSI and several other NGOs urged the Social Security Institute to comply with the constitutional mandate regarding access to ARVs. However, these efforts were not successful due to political conflicts that resulted in the Supreme Court intervention and dismissal of the case.
>
> By the end of 2003 the 'Coalition for the Right to Life and Health' was established as an NGO. It comprises of NGOs working on HIV/AIDS, hemophilia, schizophrenia, leukemia and cystic fibrosis. The reason for bringing together this array of NGOs was that all persons living with these diseases face the same problem of medicine shortage and access. The coalition carried out a number of advocacy actions to focus the government's attention on the issues related to access to medicines.

Barriers and Challenges

There have been major factors limiting access to treatment: shortage of ARVs and materials for running diagnoses, control and follow-up tests; flaws in the management of medicine delivery within the public health system; shortfall in budgetary allocation; lack of political will and bureaucratic inefficiency, among others, have been major factors limiting access to treatment. Other unforeseen circumstances have been the socio economic and political situation of the country.

TABLE 2:
Commitments on Access to Treatment & the Venezuelan Government's Response

DoC	Analysis of Venezuelan Government's Response
To establish national strategies aimed at strengthening health assistance system as of 2003.	The MHSD developed the HIV/AIDS National Strategic Plan in Venezuela in 2002 and was formally issued on April 2003. The IVSS has an access to treatment program but it is not in writing and there is no formal document to support it. This program has been applied since 1996 to date. There is no Strategic Plan available.
To address issues that affect HIV/AIDS medicine supply, including ARV treatment, such as price and accessibility, fixing differential prices as well as technical and health system capacity.	Regional Agreement for joint purchase of medicines (Lima, Peru, 2003). This Agreement has not been used to purchase ARV treatment. Protocol for Joined Technical Cooperation Action between MHSD in Venezuela and Public National School in Brazil.
By 2003, make necessary efforts to provide high quality treatment in a gradual and sustainable manner, including prevention and treatment of opportunistic diseases and efficient application of ARV therapy, carefully and under quality control surveillance so as to improve treatment.	The MHSD developed the HIV/AIDS National Strategic Plan in Venezuela in 2002 and it was formally issued on April 2003. However, it is partially executed. The document 'Guidelines for ARV Treatment in Venezuela' was prepared in 2002. Budget allocation is still Bs 50 thousand million. The National Institute of Hygiene does not run quality tests (bioequivalence and bio-availability) for ARV medicine entering Venezuela. It is estimated that 13000 PLWA receive ARV tri-therapy through public health system (MHSD, IVSS, Ministry of Defense and health regional institutes.)
To cooperate constructively in improving pharmaceutical regulations and practices as of 2003, including the ones applied to generic medicines and to intellectual property rights so as to promote innovation and national industry establishment.	To enter Protocol for Joined Technical Cooperation Action between MHSD in Venezuela and Public National School in Brazil. Stand-by negotiations. The document 'Guidelines for ARV Treatment in Venezuela' was prepared in 2002.
To make sure that national strategies be established as of 2003, in order to provide psychosocial assistance to HIV/AIDS patients, relatives and communities.	The MHSD developed HIV/AIDS National Strategic Plan in 2002 and it was formally issued on April 2003.

Written Documents (plans, policies and programs)	The MHSD developed HIV/AIDS Strategic Plan in 2002 and it was formally issued in April 2003.
Time for delivering ARVs	MHSD and the Ministry of Defense take one month to deliver ARVs. IVSS takes 15 days. However, delivery time is not fulfilled during ARV shortage in these programs. For example,there were PLWHA who did not receive ARVs during a four month period in 2003.
Experience with generic ARVs	MHSD experience is very little. At the end of 2002, three different non-proven quality ARV copies were purchased. Quality test results are still expected. The Ministry of Defense and the IVSS have no experience on these ARVs .
Legal regulations for treatment access	Laws: There is no law regulating this aspect. a.- National Constitution contains articles to guarantee right to Life and to Health b.- Venezuela entered the San José Pact which states the right to access scientific and technological breakthroughs and it is ratified in National Constitution c.- Medicine Law, 2000. Resolutions: Several resolutions have been issued: a.- No. 621 of the Ministry of Health and Social Development. Official Gazette No.37.064 dated 26.10.2000. Resolution No. 621 states health service institutions' obligation to run ELISA test in order to determine HIV presence in every pregnant women taking pre-natal control and to guarantee ARV treatment to HIV+ women during pregnancy stage, delivery and post-delivery as well as virus and immunology control in mother and newborn. b.- No.104-99 of the Ministry of Health and Social Assistance. Official Gazette. No. 36.648 dated 24.02.1999. Resolution Nº 104-99 states that activities related to AIDS and Sexual Transmitted Diseases be constituted in a single Program c.- No. SG.-439 of the Ministry of Health and Social Assistance. Official Gazette No. 35.538 dated 26.08.1994. Resolution SG-439 of the Ministry of Health and Social Assistance aims at protecting individual status and getting free consent for HIV/AIDS related tests.
To comply with commitments entered by the Venezuelan Government	IVSS officers state that there is no change in access to treatment situation after adopting the Declaration of Commitment.

(Source: Venezuelan National Report submitted to ICASO)

It is difficult to assess whether or not the adoption of the DoC has had any influence in the governments' decisions to scale up ARV access. Nevertheless in the last five years there has been significant improvement in most countries (and the four countries in this pilot study demonstrate that) at least at the policy level to guarantee access to treatment. What needs to be achieved is the implementation of these policies. Some positive steps have been taken that have resulted in a lowering in the prices of ARVs and the importation of generics. However, it is not enough. Treatment costs are still high and their availability are confined to major urban centers. Further, governments, civil society, private sector, multilateral agencies, donors and other stakeholders must work together to identify best practices and replicate them at a large scale to expand treatment to the maximum number of people in need of it. All policies and programs must reach the most marginalized and the most vulnerable to ensure non-discriminatory access. This can only be possible when access to treatment is recognized by all governments as a basic human right. Only then will the goals of the '3 by 5 Initiative' and the access to treatment commitment in the DoC be realized.

Key Recommendations

- The study clearly indicated that the biggest challenge that PLWHA face in accessing treatment is economic but this is not the only obstacle that they face. Merely having policies is not indicative of better or improved access. Implementation is crucial. A reduction in the prices of ARVs and allowing manufacture or importation of generics is critical to increase access to medication and treatment for PLWHA. This will require greater advocacy efforts from NGOs to pharmaceutical companies and governments.

- To ensure that treatment reaches all parts of the country, including rural areas and all persons in need, governments must engage in partnerships with civil society. NGOs and CBOs work at the frontlines with communities that often evade the government's reach and can be a critical resource to ensure non-discriminatory access to treatment.

- A good infrastructure should be developed for the provision of ARV therapy including investing in training of health professionals, better laboratory diagnostic facilities and greater accessibility to health care facilities where ART is available. Most of the countries studied had no plans to this effect.

- The government must engage in greater information dissemination of its treatment programs. Very often as this study indicated, PLWHA are treatment-illiterate and have no idea of the treatment options available to them.

- Civil society must be involved in the designing, planning, implementation and monitoring of all programs related to access to treatment. Their involvement must not be merely symbolic, as was the case in most of the countries studied, but rather there should be a transparent mechanism by which inputs from NGOs and CBOs are integrated into the formula-

tion and design of programs. All programs must be monitored for outputs and civil society should be a part of the monitoring process as well. For this to be a reality, training programs to build the capacity of civil society in monitoring processes must be undertaken by organizations such as UNAIDS and ICASO.

- There should be greater budgetary allocation to meet this target and better management of available resources. Civil society should monitor what governments are committing to allocate and what they are actually allocating for scaling up access to treatment. For their part, NGOs and CBOs must conduct a gap assessment before designing a program so that they do not duplicate the programs of other NGOs or the government as this can often consume the meagre resources available.

Lessons Learned:

- Merely having policies in place does not ensure access. Rather, it is the implementation of those policies that is critical. The prohibitive cost of ARVs continues to be a major barrier to access. Obtaining supplies of ARV and ensuring the sustainability of these supplies is a major challenge for PLWHA.
- Where there is little community organization or advocacy for access to ARVs, PLWHA are denied a critical resource. PLWHA networks and community and NGO activists are instrumental in enhancing access to HIV/AIDS treatment and in giving people hope.

"New infections - five million last year - are increasingly occurring among women, in particular adolescent girls. At the root of these developments is the deprived status of women in society. Fighting AIDS is therefore fighting for women's equal rights."[31]

— Marika Fahlen, UNAIDS

Empowerment of Women Commitments[32]

"We heads of State and Governments and representatives of States and Governments....."

DoC paragraph 14: Recognize that gender equality and the empowerment of women are fundamental to making women and girls less vulnerable to HIV/AIDS;

DoC paragraph 59: Commit, by 2005, to implement strategies that promote the advancement of women and their full enjoyment of human rights; promote shared responsibility of men and women to ensure safe sex; and empower women to control and decide freely on matters related to their sexuality to enable them to protect themselves from HIV infection;

DoC paragraph 60: Commit, by 2005, to implement measures to enable women and girls to protect themselves from the risk of infection, through provision of health care services, including sexual and reproductive health, and through prevention education that promotes gender equality;

DoC paragraph 61: Commit, by 2005, to implement strategies to empower women, protect their human rights, and reduce their vulnerability to HIV/AIDS by eliminating all forms of discrimination and violence against women and girls, including harmful traditional practices, abuse, rape, sexual violence, battering and trafficking.

Empowerment of Women

Since the beginning of the epidemic, AIDS has been perceived as a disease striking mainly men. Today, women account for about half of the 40 million people living with HIV/AIDS worldwide. In sub-Saharan Africa, where HIV transmission is predominantly heterosexual, almost 60 percent of the people living with the virus are women.[30]

Women are more susceptible to HIV infection because of biological, cultural and social factors. These social and cultural factors include illiteracy and lack of skills to work outside the home, forcing them to be dependent on men for economic support. Inaccessibility to accurate and reliable information on HIV/AIDS prevention and lack of capacity to use protective measures against HIV infection also increases their vulnerability.

ICASO strongly believes that gender equality and empowerment of women are fundamental to making women and girls less vulnerable to HIV/AIDS. No initiative can be successful if it leaves out half of its population and does not address their special needs but rather continues to marginalize them in all responses. Therefore, ICASO in this study focused on measures that governments were taking towards empowering its women and thus fulfilling this commitment.

The results from the research study in the four countries indicated that this is probably the most neglected area and women's issues continue to be marginalized even today when women

30 The Epidemic Now: Implications for Women and Response": statement by Marika Fahlen, UNAIDS Director, on the occasion of International Women's Day Geneva, 8 March 2004.

31 ibid.

32 Adapted from the DoC.

account for half of those infected globally. The rising infection rate among women is leading to a recognition of this problem on the part of some governments forcing them to act. In Kenya, there has been a 20 percent increase in HIV infections among women during the last three years forcing the government to adopt a gender sensitive approach in its HIV/AIDS programming. In the Philippines, women's organizations are represented on the Philippine National AIDS Council (PNAC). Further, women's issues were incorporated into the Philippine AIDS Prevention and Control Act adopted in 1998 but it is yet to be implemented. Regarding Ukraine, the study revealed that though a number of policies exist, these are rarely implemented. For example, although policies and procedures are in place for all cases of rape or sexual abuse of women, more often than not these are ignored by those who should implement them. In Venezuela, there are practically no interventions that focus exclusively on women.

Once again, these findings highlight the need for civil society to be actively involved in the monitoring of the implementation of the DoC because it is not simply enough to have policies, laws and procedures in place, but these need to be implemented, respected and enforced.

Kenya

Initiatives taken by the Government

Kenya is one of the few countries in the world where HIV/AIDS is growing faster among women, particularly among married women. Sexual intercourse is the primary mode of transmission. In the last three years, the prevalence rates among women was reported at 40 percent but today, out of the total number of those infected, 60 percent are women. By the end of 2002, 1.4 million women, as opposed to 900,000 men, were infected with HIV.[33] However, the government has not yet identified women as a group that is particularly vulnerable.[34] Initially the Kenya HIV/AIDS Strategic Plan did not include gender issues. In 2001, following the adoption of the DoC, as the gender aspects of the epidemic became clearer, it was recognized by the Government that gender and power relations played a very important role in the dynamics of the HIV/AIDS pandemic. The National AIDS Control Council thereafter established a technical sub-committee on Gender and HIV/AIDS and it was agreed that the best approach would be to make the existing Kenyan National HIV/AIDS Strategic Plan gender sensitive since it is a key document that guides and coordinates all responses to HIV/AIDS in Kenya. Further, the Kenyan government has committed itself to mainstream gender issues in its legislation, policies, guidelines and programs. A guideline on how it intends to do so has also been developed, but it is yet to be implemented.

Female Condom

The female condom is a tool to empower women to control their sexuality. However, the female condom is not easily available and is more expensive than the male condom. Consequently, the prospects for its popularity and widespread use are not yet clear. The Reproductive Health Advisory Board (MoH) will monitor its inception in the market and will be responsible for mobilizing resources for making it available. The government's position will have a definite impact on women's empowerment by giving them the ability to take control over their bodies and not have to negotiate condom use with their male partners.

Civil Society Response

Civil society responses towards empowering women have primarily focused on production and dissemination of IEC material and strengthening women's capacity through training programs to better understand their health needs.

MADRE, an international human rights organization for women, supported the Indigenous Information Network's workshops for Maasai women on women's rights within the family, the community and internationally. The workshops focused on HIV/AIDS education and the collective land rights of indigenous women.

The Young Women's Christian Association (YWCA), Kenya has implemented community health programs and long term empowerment strategies to bring HIV/AIDS to the forefront of YWCA advocacy work at local, national and global levels. [35]

[33] Mainstreaming Gender into the Kenya HIV/AIDS Strategic Plan 2000-2005 (November 2002): This is a policy document published by the National AIDS Control Council as an additional tool for practical use in planning gender sensitive strategies and interventions. Copies of these can be obtained at National AIDS Control Council, National AIDS and STI Control Program, or KANCO Resource Centers.

[34] Progress Report submitted by Kenyan government to UNAIDS.

[35] Source: Web sites of MADRE (http://www.madre.org) and YWCA, Kenya (http://kenyaywca.org).

Barriers and Challenges

A number of challenges impede progress towards realizing this commitment. The economic decline in the country has slowed the implementation of programs for the rights of women as the government is channeling funds to other areas of development; there is poor dissemination of HIV/AIDS information among women and in some cases HIV/AIDS information is also not gender sensitive; illiteracy rates are still high among women in Kenya. This has hindered the promotion of their rights and has increased their vulnerability to HIV/AIDS. Finally, in most Kenyan communities culture is a barrier to promoting the rights of women as women have an inferior status to men. Some cultural practices such as female circumcision as well as lack of decision-making authority also increase the chances of women contracting HIV/AIDS.

Philippines

Initiatives taken by the Government

The Philippine AIDS Prevention and Control Act of (1998) provided a base for developing policies and plans to address HIV/AIDS. Women's concerns and issues have been incorporated into the Act. This Act was enacted long before the DoC was adopted. The '2000-2004 Medium Term Plan for Accelerating the Philippines Response to HIV/AIDS' includes strategies to implement the Act at the community level. However, these strategies have not yet been implemented.

Female Condom

As in any developing country, female condoms are not readily available. However, the Department of Health is currently conducting research to make the female condom available. The potential barriers that might have to be overcome include the strong influence of the Catholic Church that opposes the use of any contraceptive measure; lack of information about the benefits (and risks) of the female condom among women; and the availability of other alternative contraception devices that are more acceptable, available, accessible and cheaper.

Civil Society Response

The Philippine government has a poor system of documenting human rights violations of PLWHA and particularly positive women. This situation has been somewhat addressed by NGOs that have produced or developed information kits for HIV+ women. Further, women in a patriarchal society like the Philippines do not enjoy entitlements, particularly so if one is HIV+. Consequently, NGOs with women as their target population do their share by advocating for greater involvement of women. They do this by encouraging positive women to become agents of social change through peer education and counseling.

"I am HIV positive and I got infected by my husband who was a seafarer. Up to now, I am treated as an outcast .... Positive women need care and support not discrimination and isolation. We need counseling and help on medication and treatment. Our government is slowly providing antiretrovirals. We want to be accepted by the community and live as anybody else."

– Maria (not her real name), HIV/AIDS Counselor and Advocate
Positive Action Foundation, Philippines

Barriers and Challenges

Women in Philippines continue to face a number of barriers that hinders their empowerment. Though economic factors, such as their economic dependence on men, play an important role, these are by no means the only factor. Women continue to be disempowered

because of cultural reasons and women's health care needs are seen as secondary. Further lack of information and access to female condoms and the proper use of condoms in general continue to pose a challenge. Even when poor women have access to health care providers, they often hesitate to obtain services as the attitudes of service providers are not encouraging. HIV+ women face dual discrimination, one because they are women and second, because of their positive status.

TABLE 3: Commitments on Empowerment of Women and the Philippine Government's Response[36]

DoC	Analysis of Philippine Government's Response
By 2003, implement multi-sectoral strategies and finance plans (paragraph 37)	The Republic Act 8504 is the strongest commitment of government support to HIV/AIDS prevention and control. The 2000-2004 Medium Term Plan for Accelerating the Philippine Response to HIV/AIDS The Philippine National AIDS Council (PNAC) coordinates and overseas HIV/AIDS prevention and control programs and activities. Women's groups are duly represented in the Council. The Philippines implements a Gender and Development program where HIV/AIDS is included. It aims to increase awareness among civil society through trainings, workshops and other forums.
By 2003, integrate prevention, care, treatment, support and mitigation priorities into development planning (paragraph 38)	At the national level, 'HIV/AIDS and Women' are a major part of the Philippines Health Development Plan. The Philippines Department of Health Women's Development Unit provides technical assistance on women's concerns in reproductive health including sex and HIV/AIDS. At the local level, Local AIDS Councils (LACs) monitor HIV/AIDS prevention programs in their locality.
By 2005, implementation prevention and care programs in the workplace supportive environments for people living with HIV/AIDS (paragraph 49)	All government units and bureaucracy have a women's desk that responds to HIV/AIDS, Reproductive Health and sexuality issues at the workplace. These desks document cases of discrimination. An existing 'National Workplace Action Plan' on HIV/AIDS and STDs spells out the program of action that should be instituted by agencies. The 'National Workplace Policy' guides management and workers on how to handle STD/HIV/AIDS situations in the workplace.
By 2005, implement prevention and care programs for migrant workers with information on health and social services (paragraph 50)	All overseas Filipino workers undergo a 45-minute pre-employment departure orientation seminar (PDOS) where HIV/AIDS is one of the various topics discussed. Filipinos living with HIV/AIDS were invited to provide a human face to HIV/AIDS by giving HIV/AIDS lectures and testimonies during PDOS. The Philippines government is active in raising migration as a regional issue in the ASEAN Task Force on AIDS (ATFOA) but no regional response has been generated. Filipino women work as domestic helpers in most of the ASEAN-member countries.
By 2003, develop programs, recognizing the importance of family, culture and religion, to reduce vulnerability of children and young people.... (paragraph 63)	The Philippines has passed the Republic Act 7610 (the Anti-Child Abuse Act) which protects children especially the girl-child, from labor, physical, psychological and sexual abuse and exploitation.

[36] Data included in this matrix were culled from a draft evaluation of the participation of the Philippine government vis-à-vis UNGASS in January 2004; see Philippines National Report to ICASO.

Ukraine

Initiatives taken by the Government

There are practically no measures for the prevention of HIV/AIDS infection and for the protection of the rights of HIV+ women. Information on the number of women infected is not available and gender aspects of the epidemic are disregarded in nearly all existing literature on HIV/AIDS. The level of knowledge among women about HIV/AIDS and problems related to unsafe sex is also very low.[37] As far as this commitment is concerned, very little action has been taken by the government. Though there are protocols for police officers and medical services prescribing measures that should be taken in all cases of rape and sexual abuse these are frequently ignored. In reality, only a medical examination is provided, which is usually not comprehensive.

According to a representative of the Women's Network (an NGO), there is gender discrimination in Ukraine in terms of access to ARVs. The peculiarity of the fight against HIV/AIDS in Ukraine is that it primarily addresses IDUs, which is why treatment is most accessible to heterosexual, male rehabilitated drug-users. For women, as well as homosexual men, it is harder to access treatment or other HIV/AIDS related services.

"It is not that women are not getting treatment because of their gender but rather because of not conforming to stereotypes or heterosexual standards.... There are also numerous cases of violation of the rights of HIV+ women to have a child and receive necessary medical assistance.[38]"
— Women's Network Representative

Civil Society Response

Due to lack of government commitment and action, civil society has taken upon itself to address the health needs of women. But these are by no means enough. For example, the Women's Network has conducted training programs on issues related to safe sex and human rights; they have also developed IEC materials, and have conducted capacity building programs aimed at developing women's leadership skills.

Barriers and Challenges

The major barrier in Ukraine is that most initiatives of the government and even NGOs are targeted towards IDUs and particularly male IDUs due to the high infection rates among that group. Thus issues such as educating women on prevention measures and instituting programs for empowering women is not considered to be a priority.

"In the last two years, women's awareness of safe sex practices and their ability to insist on condom use has not improved. The problem is that men rarely listen to women's opinion as far as condom use is concerned. Therefore, all efforts to educate people about safe sexual practices in Ukraine should target not only women, but also men.[39]"
— Women's Network Representative

[37] Information obtained from representative of 'Women's Network'.
[38] ibid.
[39] ibid.

Venezuela

Initiatives taken by the Government

In Venezuela, sexual intercourse continues to be the most common mode of infection. More than 90 percent of PLWHA have been infected this way. After the adoption of the DoC, the importance of the issue of women and HIV/AIDS was recognized. This was also due to the rapid rise in infection rates among women. In the last few years there has been a significant increase in the number of women who have been infected, particularly those between 20 to 34 years of age. However, few initiatives have been taken in spite of the growing concern. Sexual and reproductive health services in Venezuela are inadequate. Likewise, health policies targeted to raise awareness among women about their sexual and reproductive health and rights are insufficient. There is no policy to empower women and to reduce the risks associated with unprotected sex, such as distribution of the female condom. The Ministry of Health has established a medical protocol for all cases of violence and sexual abuse. However, there has been no dissemination of information or training of health professionals to implement it. Hospital personnel in most cases do not know how to handle these cases.

Female Condoms

Female condoms in Venezuela are very expensive and not well known. Their free distribution is carried out in a very limited way by the National AIDS Program. Some international organizations also supply them to local NGOs, but these are not widely known or used. In addition to access difficulties, there are a number of obstacles to their use, such as the social understanding of sexuality. Women have usually left issues of sexual decision-making in the hands of their male partners and are not empowered to take control over their own sexuality by using the female condom. Likewise, some beliefs and misconceptions about using condoms such as less pleasure and infidelity issues may make negotiations for women more difficult.

> *“…if someone undertook a national survey about the female condom, I assure you that the majority of both (men and women) are not even aware that it exists. The fact of using a (male) condom is not even contemplated unless having sex with a sexual worker. And, this is the mentality of men and women; which somehow reflects the difficulties our women have to go through, ‘how can we ask them to wear a condom...he will think I’m a prostitute.”*
> *– Fundación Santa Clara (FSC) Representative*

Civil Society Response

Most women's organizations that deal with sexual and reproductive health issues or with women's issues in general have not yet included HIV/AIDS in their program priorities. They address women's issues from the perspective of family planning, pregnancy and sexual violence. In the course of this research, only two NGOs that address the concerns of HIV+ women were identified: FSC and MUSAS. [40]

"If you do not have the resources to pay for a medical visit, it is very hard to find a good doctor, a clean and decent place, where personnel do not treat you badly, or call you 'the woman with AIDS' in front of the rest of the patients... or, leaves you last even if you were first in line. In addition to poverty, there is ignorance, that overwhelms you with fear, and from which a doctor cannot get you out in a public consultation, where he can only spare a couple of minutes for each patient;...many of these women are widows and have spent all their economic resources supporting their husbands before they died, besides they need to support their children, buy medication, etc. Having pills is not enough, you must know how to use them, what to do in case of side effects and complications. And on top of it all, you need to develop a habit and discipline to take them."
– Fundación Santa Clara (FSC) Representative

Barriers and Challenges

As per the government's policies there is equal access to treatment and care, as well as support and prevention services for all persons regardless of gender. However, in practice, women face a number of obstacles and barriers in accessing them. Some of these are due to the smaller percentages of infected women (according to official estimates) which undermine the magnitude of their problem in accessing treatment and a small number of health professionals who have been trained to address the specific problems of HIV+ women. There are no health centers exclusively for HIV+ women. Even in hospitals, that treat PLWHA, the number of beds designated for women is fewer than the number of beds designated for men.

[40] Fundación Santa Clara (FSC) and Asociación de mujeres (MUSAS).

The research study indicated that the adoption of the DoC has had no impact in reducing the vulnerability of women to HIV/AIDS. This has been one of the most neglected area in terms of governments' response to the AIDS epidemic. Also civil society initiatives towards fulfilling this commitment in the four countries that were studied have been limited. It is probably due to these reasons that infection rates are rising among women and today out of those infected globally, 50 percent are women. To stem the tide of the epidemic the magnitude of this problem must be recognized and critical steps must be taken by governments and civil society towards empowering women and reducing their vulnerability to HIV/AIDS infection.

Key Recommendations

- To achieve this commitment, effective outreach programs need to be developed with a high priority on strengthening sexuality and gender information, education, supportive counseling and follow up services. Inaccessibility to accurate and reliable information on HIV/AIDS prevention and lack of capacity to use protective measures against HIV infection increases women's vulnerability. Hence, information, education and communication materials for the promotion of safe sexual behavior need to be disseminated and widely available. Given women's lack of empowerment, these programs should target not only women but also men to have an impact on cultural perceptions to bring about behavioral changes.

- Women's organizations must be involved in developing all policies and in designing programs related to HIV/AIDS to ensure that they are gender sensitive and take into account women's issues. Gender issues must be built into projects at all stages including project design, implementation, monitoring and evaluation. There should be adequate representation of women at all levels of decision-making. It is critical to feed the needs and wants of women into all policies and programs.

Lessons Learned:

- Gender related inequalities threaten the right to health and increases vulnerability to HIV infection.
- Economic empowerment increases individual and collective capacities for HIV prevention, access to treatment and care.
- Engaging men and women in the response to HIV/AIDS is critical to bring about changes in social perceptions of gender relations and in achieving behavioral change.

- Governments must fulfill their obligations under international law such as the CEDAW[41] that prohibits discrimination against women and ensures that their rights are protected. For example, all governments must enact legislation against discriminatory practices such as female genital mutilation, that fuel women's vulnerability to infection.

- Public health programs should have special provisions for sexual and reproductive health. The female condom should be promoted as a tool for empowering women to take control over their bodies and not have to negotiate condom use with their male partners.

- Social constructions of gender roles force women to be dependent on men for economic support. From this economic dependence arises unequal gender and power relations in decision-making which hinders women's ability to negotiate condom use making them more susceptible to infection. To address this economic imbalance, the government in partnership with civil society must design programs to support women's economic independence. For example by providing micro-credit facilities, income generating cooperatives, and other initiatives to enhance their employability.

41 Convention on the Elimination of all forms of Discrimination Against Women.

Human Rights of PLWHA and other Vulnerable Groups

Human rights are fundamental to any response to HIV/AIDS. The promotion and protection of human rights are necessary to empower individuals and communities to respond to HIV/AIDS, to reduce vulnerability to HIV infection and to lessen the adverse impact on those affected. The incidence and spread of HIV/AIDS are disproportionately high among groups that already suffer from a lack of human rights protection, and experience stigma and discrimination. This includes groups that have been marginalized socially, culturally and economically; for example, injecting drug users (IDUs), sex workers, men who have sex with men (MSM) and PLWHA. These groups will not seek counseling, testing, treatment and support if this means facing stigma, discrimination and lack of confidentiality as well as other negative consequences. Discriminatory measures and other coercive actions drive away the people most in need of services.

In spite of negotiations during the UNGASS, the adapted version of the DoC does not explicitly mention the different vulnerable groups. For this particular research, ICASO asked the in-country researchers to seek information on the human rights situation of PLWHA and one of the three vulnerable groups reflecting their national priorities: men who have sex with men (MSM) in Venezuela, sex workers in Kenya and Philippines and injecting drug users (IDU) in Ukraine.

In all four countries, PLWHA are protected by law against discrimination. However, in practice, PLWHA and other vulnerable groups are still subject to discrimination and stigma. NGOs and PLWHA groups, through advocacy to governments have been championing for the protection of their human rights and those of other vulnerable groups by making information, prevention and treatment accessible to all.

Human Rights of PLWHA and other Vulnerable Groups Commitments[42]

"We heads of State and Governments and representatives of States and Governments….."

DoC paragraph 13: Recognize that stigma, silence, discrimination and denial, as well as lack of confidentiality, undermine HIV prevention, care and treatment, and increase the impact of the epidemic on individuals, families, communities and nations;

DoC paragraph 58: Commit, by 2003, to enforce legislation, regulations and other measures to stop discrimination against people living with HIV/AIDS and vulnerable groups, and to ensure all their rights – in particular, their access to education, inheritance, employment, health care, social services, prevention, support, treatment, information, legal protection, privacy and confidentiality; and develop strategies to combat stigma and social exclusion;

DoC paragraph 96: Commit, by 2003, to establish monitoring systems for the protection of human rights of people living with HIV/AIDS

[42] Adapted from the DoC.

Kenya

Persons Living with HIV/AIDS (PLWHA)

Initiatives taken by the Government

Recently, the government took a significant step in the fight against HIV/AIDS by approving a Bill that would criminalize discrimination against PLWHA. The Bill proposes to make it criminal for an employer to fire a person or deny them a job because of their HIV status. But despite this new Bill, as well as other provisions, PLWHA are still discriminated against in the workplace, the church and in society at large. The rights of PLWHA are not enforced strongly. In fact, the civil court system in Kenya is not conducive to the needs of PLWHA since it encourages publicity of cases that may generate stigma and hostility against them.

According to the Kenyan Progress Report to UNAIDS, the government recognizes that it faces two main challenges in developing human rights policies on HIV/AIDS: lack of acceptability and clash with cultures and professional ethics.

Civil Society Response

Networks of PLWHA have been at the forefront for promoting and protecting the rights of their members. They are also in the frontline to ensure that PLWHA are involved in the development of any programs or policies that directly or indirectly affects them, thus implementing the Greater Involvement of People Living with HIV/AIDS (GIPA Principle).

GIPA PRINCIPLE

The GIPA Principle as set out in the 1994 Paris Declaration advocates that People Living with HIV/AIDS have a crucial role to play in all HIV/AIDS management and prevention strategies. They have been the cornerstone to numerous interventions around the world and can bring to the table critical issues.

“We know AIDS is real in Garrisa town, but dealing with a drunk is just a problem. They demand sex but they do not care if they used condoms or not and because you need money you are left with no choice... as the prices of female condoms are too high.”
— Key informant

Vulnerable Group: Sex Workers

Initiatives taken by the Government

Although the government of Kenya has taken some steps toward the protection of the rights of vulnerable groups, sex workers still lack such protection. In Kenya, sex work though not expressly stated in the law, is considered to be an immoral and illegal trade and sex workers continue to be marginalized. This has led to their lack of inclusion in some of the government’s programs.

Civil Society Response

Given the lack of government action targeted towards sex workers; a number of NGOs and CBOs have initiated programs to address the unmet needs of this group. The sex workers have themselves started self-help groups to help them fight and cope with HIV/AIDS by creating awareness among their peers. The government has provided, in some cases, funds for such initiatives.

The silence and denial surrounding male sex workers in Kenya has left them unable to access basic services addressing HIV/AIDS and their sexual health needs. Key barriers in Kenya include official denial of their existence, social marginalization and lack of information about their needs and concerns. Hostile and discriminatory attitudes from health care workers make them reluctant to use the existing health services. Most of them resort to self-medication because of the discrimination that they face while visiting health centers. The police also constantly harass male sex workers and do not respond to their complaints when their clients' sexually abuse them.

Philippines

Persons Living with HIV/AIDS (PLWHA)

Initiatives taken by the Government

A major accomplishment of the Philippine government in addressing AIDS was the adoption of the AIDS Prevention and Control Act in 1998. The Act, which was the first of its kind in the Asia-Pacific region, is a concrete step taken by the government to safeguard the human rights of PLWHA. Among the important provisions of the Act are the prohibition of mandatory testing; protection of PLWHA from discrimination in the workplace, schools, health facilities and the promotion of medical confidentiality. However, in reality, the link between HIV/AIDS and human rights is not well understood and a rights-based approach (RBA) to programs, particularly in education and information activities has not been integrated. In reality PLWHA continue to experience human rights violations even after the adoption of the Act.

The Alternative Law Research and Development Center, Inc. (Alterlaw) in its assessment[43] of the Philippine government's observance of the International Guidelines on HIV/AIDS and Human Rights, through the implementation of the AIDS Prevention and Control Act, asserted that although the Philippine government is serious in its attempt to address both the public health and human rights issues related to HIV/AIDS, the emphasis of the law has been more on the medical and ethical aspects. This has contributed towards addressing the HIV/AIDS problem more as a medical rather than a developmental and human rights problem.

Civil Society Response

Many PLWHA groups have taken it upon themselves to provide services to their members that should have been the responsibility of the government such as helping them access medications or providing counseling (see section on Philippines-Access to Treatment).

Vulnerable Groups: Sex Workers

Initiatives taken by the Government

Although the AIDS Prevention and Control Act contain non-discriminatory provisions for PLWHA, there are no specific provisions for non-discrimination of vulnerable groups. Advocacy actions have been carried out by NGOs for anti discriminatory measures, but policies and laws have not yet been formulated or enacted. In addition sex work is not legal in the Philippines. In many cities and urban centers, women employed in entertainment/recreational establishments (e.g., bars, clubs, and massage/sauna parlors) are required by local laws to take mandatory medical screening/check-ups in Social Hygiene Clinics.

“(Policemen) believe we are bad and shouted that we are just ‘jokards’ (street label for prostitutes). What right do you have to complain? Sir, I told him, even if we are the ones abused? Is it because a police is involved that we lose our rights? He told me,– ’customer is always right.”
– Key informant

43 Alterlaw, Where are we now? A candid snapshot of Philippine Observance of International Guidelines on HIV/AIDS and Human Rights, December 2003, p. 26.

Based on the test results, they are issued “pink cards” or “social hygiene cards” indicating that they are fit to work. Such a law perpetuates discrimination.[44]

“There was a woman who came for a check-up. I was there writing down their names for this NGO. Then I heard one of the male staff ... a member of the maintenance ... 'Chances are she (referring to the women being examined) already has AIDS because she is a ‘pokpok’ (street label for prostitute) in Cubao.’ He does not know I am also a ‘pokpok’. I did not return.”
– Key informant

Some efforts have been made by the government but these have been limited to education and training programs for law enforcement agencies and personnel on the health needs of sex workers. However, these measures do not seem to have had any impact on sensitizing the police force.

44 Based on interview with an AIDS NGO officer, December, 2003.

Ukraine

Persons Living with HIV/AIDS (PLWHA)

Initiatives taken by the Government

In Ukraine, legislation exists for the protection of the rights of PLWHA and other vulnerable groups. However the problem lies in the lack of implementation and violation of these laws. For example, the provision on the 'Law on AIDS' states that the 'registration and record-keeping of HIV-infected persons and PLWHA, as well as medical care for them, must be affected by observing principles of confidentiality and respect for personal rights and freedoms of humans as designated by the laws and international treaties of Ukraine'. In practice there are no mechanisms to protect the right to confidentiality of those infected and diagnosed as positive. On the contrary, there are normative acts that directly violate the human rights of PLWHA. For example, an employer can demand information about an individual's HIV-status during a job placement. According to NGO representatives, there are no special programs or policies for protecting the rights of PLWHA.

Civil Society Response

NGOs are implementing programs designed to reduce stigma, social exclusion and discrimination against PLWHA. Some of their activities include seminars and training programs for teachers and social workers, appearances of HIV+ people in the mass media, education programs at schools, charitable public performances and dissemination of IEC materials.

Monitoring of the human rights of PLWHA has been undertaken by the All-Ukrainian Network of PLWHA and the Odessa-based NGO Life+. The All-Ukrainian Network of PLWHA has also launched media campaigns to reduce the stigma and discrimination against those infected and affected by HIV/AIDS and to sensitize the general population by providing a human face to the disease. (See section on civil society involvement)

Vulnerable Groups: Injecting Drug Users (IDU)

Initiatives taken by the Government

Ukraine has adopted legislation to facilitate access to prevention services, HIV/AIDS education, employment, social services, medical help, and voluntary counseling and testing (VCT) for IDUs. Further, the Cabinet of Ministers of Ukraine has decided to create government centers for rehabilitation of drug users. However, according to most NGO representatives, often the bias of judges and employees of law enforcement agencies makes it impossible for vulnerable groups to adequately protect even their basic rights.

"The government's decision that drug use should not be grounds for refusal of ARV treatment may serve as an example of positive government intervention to prevent discrimination against vulnerable groups. Before this decision, injection drug users did not have access to ART"
– NGO Representative

Civil Society Response

Access to information on prevention for vulnerable groups is achieved through dissemination of IEC materials by NGOs. Training programs are also conducted by local/national NGOs and international organizations.

> *"It is fair to state that the main work on human rights protection, information and prevention of HIV/AIDS for vulnerable groups is carried out by NGOs."*
>
> *– Key informant*

TABLE 4: Commitments on Human Rights of PLWHA and Other Vulnerable Groups and the Ukrainian Government's Response

DoC	Analysis of Ukrainian Government's Response
By 2003, commit to enforce legislation, regulations and other measures to stop discrimination against PLWHA & other vulnerable groups, and to ensure all their rights – in particular, their access to education, inheritance, employment, health care, social services, prevention, support, treatment, information, legal protection, privacy and confidentiality; and develop strategies to combat stigma and social exclusion.	The Government of Ukraine has adopted legislation for the protection of the rights of PLWHA and IDUs to facilitate their access to prevention services, HIV/AIDS education, employment, access to social services, medical help, and voluntary counseling and testing (VCT).
Commit, by 2003, to establish monitoring systems for the protection of human rights of people living with HIV/AIDS	No monitoring system has been established yet.

Venezuela

Persons Living with HIV/AIDS (PLWHA)

Initiatives taken by the Government

In Venezuela there are laws and regulations that protect the human rights of PLWHA. In 2001, the Office of the Public Defender released a memorandum that not only emphasized that the rights of PLWHA are the same as the rest of the population but also recommended that the State design and implement policies that ensure the rights to health and to life for all PLWHA. These were adopted prior to the DoC and were thus not a result of the latter. However, what is problematic is the interpretation of these laws by individuals. For example, even though the law prohibits mandatory HIV testing, many employers still require medical examinations. Individuals who do not agree to get tested often risk losing their jobs. This coerced but yet "consensual agreement" is against the spirit of the law and violates the rights to equality and non-discrimination. The rights are further violated by doctors and private laboratories that provide employers with the test results breaching the right to confidentiality. This practice continues due to poor monitoring on the part of the government.

Civil Society Response

NGOs including PLWHA groups in addition to providing direct services to PLWHA have carried out a number of advocacy activities to push governments to create and implement policies that respect international human rights norms. Human rights activists and PLWHA groups were instrumental in securing treatment access for all PLWHA free of charge through the legal system. Networks of PLWHA do their share by advocating for greater involvement of PLWHA by encouraging them to become agents of social change through peer education, counseling and other measures.

Vulnerable Groups: Men who have Sex with Men (MSM)

Initiatives taken by the Government

The National Strategic Plan on HIV/AIDS sets a zero tolerance rule regarding discrimination related to HIV/AIDS, including questions of "sexual identity". Also, the National AIDS Program supported seven community based projects that addressed the needs of MSM in 2001. This, however, was not due to the DoC as a decision on the implementation of the project took place before the DoC was adopted.

Civil Society Response

NGOs offer a variety of programs, specially related to human rights for MSM groups to reduce their vulnerability to HIV infection. NGOs also provide information to them about safe sex, use of condoms and lubricants, HIV/AIDS, and STDs.

In 2003, Alianza Lambda de Venezuela and Sociedad Wills Wilde, sponsored by Sinergy and Proyecto Políticas and financially supported by USAID; carried out advocacy activities aimed at setting priorities within the National Strategic Plan on HIV/AIDS that address the needs of MSM groups.

From the study in the four countries, it is difficult to evaluate whether the measures that governments have taken are the result of the adoption of the DoC. However, it is clear that even three years after since the adoption of the DoC, PLWHA and other vulnerable groups continue to face stigma and discrimination which hinders their access to HIV/AIDS related services. It has now become amply clear that the relationship between HIV/AIDS and human rights highlights the ways in which people vulnerable to human rights violations and neglect are more vulnerable to HIV/AIDS infection and if infected do not have access to appropriate quality care and treatment.[45] The findings indicate that in some countries like Kenya, human rights legislation was enacted as a result of the adoption of the DoC. However, in others like the Philippines where such legislation already existed, no steps have been taken to ensure their implementation. Governments must adopt measures to meet their international obligations as outlined in the various treaties and conventions that they have ratified towards respecting, protecting and fulfilling the human rights of all persons and take specific steps towards ensuring that the rights of the most excluded are protected.

Key Recommendations

- All programs addressing HIV/AIDS must be based on the normative framework of human rights to be able to reach the most marginalized and vulnerable communities and to empower them. All programs must be guided by the needs and rights of the community while simultaneously empowering those same communities to broaden their participation and strengthen their relationships with government, law and policy makers and partner organizations.[46]
- Ensure full participation of PLWHA and other vulnerable groups in all HIV/AIDS policies and programs including planning, designing, implementation and monitoring. This participation should not be merely token, such as having few reserved seats on different HIV/AIDS government bodies but rather their inputs should be taken into consideration for all activities in a transparent manner.
- Better dissemination of IEC materials and information campaigns by using popular media to reduce the stigma and discrimination associated with HIV/AIDS.
- Indicators to measure the implementation of human rights policies should be developed.

Lessons Learned:

- Implementation of international human rights standards can be achieved at the country level by initiating advocacy activities including lawsuits.
- Having human rights legislation is not enough, rather there should be structures for the redress of all human rights violations.
- The media can be used as a tool for challenging existing stereotypes and educating the public on the human rights of PLWHA and other vulnerable groups.

[45] Based on interview with an AIDS NGO officer, December, 2003.

[46] Mainstreaming HIV/AIDS Using Community Led Rights Based Approach, ACCORD Tanzania.

Resource Allocation

For any systemic response to the AIDS pandemic, adequate resources need to be available and channeled into appropriate programs. Thus, an important element in monitoring governments' response to the pandemic is to examine the allocation of funds to alleviate the havoc caused by HIV/AIDS.

The four national reports of this project study brought into sharp focus the resource gaps that exist at country level for addressing HIV/AIDS. These gaps exist despite the commitments governments made to the DOC to increase their budgetary allocations for HIV/AIDS programs. None of the four countries that were studied have fulfilled this commitment. AIDS continues to be a developmental issue but there are often other issues that receive preference in developmental priorities.

Another issue that emerged from the study was that funds assigned for the community sector, in many cases do not reach them.

Unfortunately, information on actual allocation of resources for specific program areas was not available in most countries, nor were the overall AIDS budget that formpart of the health allocation in some cases.

Resource Allocation Commitments [47]

"We heads of State and Governments and representatives of States and Governments....."

DoC paragraph 82: Commit to increase and prioritize national budgetary allocations for HIV/AIDS programmes and ensure adequate allocations from all relevant ministries;

DoC paragraph 9: Recognize that, at the Abuja special summit in April 2001, African Heads of State committed themselves to allocating at least 15 percent of their annual budgets to improving the health sector to help address HIV/AIDS;

DoC paragraph 29: Recognize that national and regional capacities must be strengthened in order to fight HIV/AIDS effectively and that this will require increased and sustained human, financial and technical resources through strengthened national action and cooperation and increased regional, subregional and international cooperation;

DoC paragraph 90: Commit to support the Global Fund to finance an urgent and expanded response to the epidemic based on an integrated approach to prevention, care, support and treatment.

47 Adapted from the DoC.

Kenya

The population of Kenya is estimated at 30 million; 56 percent of the population lives on less than US$ 1 per day.

National Expenditure on AIDS

The implementation of the Kenyan HIV/AIDS Strategic Plan 2000-2005, requires 14,059 million Kenyan shillings (Approx. US $180 million) distributed as follows:

TABLE 5: Estimated Resource Requirements in Kenya (2000-2005) (in Kenyan Shillings in millions)

Priority Area	Actual	Expected	Funding Gap
1. Prevention and advocacy			
Promotion of behavior change	5,388	5,100	288
Prevention of blood borne infection	1,310	250	1060
Treatment and control of STD infections	597	10	587
Prevention of mother to child transmission	866	73	793
2. Treatment and support for continuum of care and support of the infected and affected	2791	146	2645
3. Mitigation of the social economic impact	785	730	55
4. Monitoring, evaluation and research	411	146	265
5. Management and coordination	1911	1280	631
Totals	14,059	7735	6324

(Source: adapted from the Kenya Proposal to the Global Fund)

As per the 2001-02 budget, the allocation to the Ministry of Health was Ksh 10,527 million (approx US $137 million) or 3.97 percent of the total budget. According to the in-country report a resource gap of almost US $180 million for the treatment and control of HIV/AIDS, treatment of STIs, and for surveillance and voluntary counseling and testing has been estimated for the period 2002-2006.

Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM)

In September 2003, the Global Fund to Fight AIDS, Tuberculosis and Malaria released US $52 million to the Kenyan Government for a two-year period. Out of this, US $37 million will be used to address HIV/AIDS. NGOs will receive a part of this money while the Ministry of Health will oversee administration of the remaining money.

Civil Society Organizations (CSOs) are represented on the Country Coordinating Mechanism (CCM) and can access the GFATM funds. In addition, a number of NGOs have independently (outside of the CCM) applied for funds to the Global Fund. To date, only two proposals from organizations have been approved. The two organizations are the Kenya Network of Women Living with HIV/AIDS (KENWA) and Sanaa Art Promotions.

Civil Society Response

The government has channeled some funds to community groups for HIV/AIDS programs. The National AIDS Council has released Ksh 102 million (approx US $1.3 million) to NGOs and CBOs. The funds are to be utilized for treatment and home-based care programs. To this end, the National AIDS Control Committee (NACC) has been restructured and the Constituency AIDS Control Committees (CACCs) have been strengthened to provide better services to communities. The Constituency AIDS Control Committees are subdivisions of the National AIDS Control Committee at the community level, through which funding should reach grassroots organizations. Besides approving projects for funding, the CACCs mandate is to coordinate and manage HIV/AIDS activities in their respective constituencies. However, 55 percent of the respondents in the in-country survey reported that they had no access to resources.

Barriers and Challenges

Most of the organizations interviewed said that the funding mechanisms are not efficient because only a small percentage of NGOs have actually received funds. Knowledge on the existence of the CCM is also poor among civil society organizations (CSO). Most CSOs were not aware that they are represented through various organizations.

TABLE 6: Commitments on Resource Allocation and the Kenyan Government's Response

DoC	Analysis of Kenyan Government's Response
Increase national budget allocations for HIV/AIDS and ensure adequate allocations from all relevant ministries (paragraph 82).	The government has not allocated what it should. Instead the health allocation is only 3.97 % of the overall budget. Also, a resource gap of US $180 million has been estimated for the period 2002-06 for HIV/AIDS programs

Philippines

Funding for HIV/AIDS in the Philippines as elsewhere in the region is still inadequate. While major health improvements have been evident during the last decade, their pace and scope now risk being overwhelmed by a growing population, a constrained economy and the various challenges to service delivery.

National Expenditure on AIDS

The total health expenditure went up by PhP 5.9 billion[48] (US $105 million) from 2000 to 2001. Private sources contributed most to the increase with a PhP 6.6 billion (US $117 million) contribution, followed by social insurance contributing PhP 1.2 billion (US $21 million). However, the government's contribution did not increase, but recorded a PhP 1.9 billion (US $34 million) decline in health expenditure. Of the PhP 119.4 billion (US $2.12 billion) total health spending of the country in 2001, the biggest share of PhP 65.4 billion (US $1.16 billion) was spent by private sources, while government and social insurance spent PhP 44.7 billion (US $793 million) and PhP 9.3 billion (US $165 million), respectively.

This indicates that health is not a priority for the government and their contributions have not changed (but have decreased) despite the UNGASS commitments.

The health budget allocation is decreasing for the last three years compared to the total or general budget appropriation. Within the health budget allocation, the AIDS program had the following amount for the years 2000 to 2003. As indicated, the budget in real numbers has declined since 2001.

TABLE 7: Health Budget Allocation in Philippines (2000-2003)

Year	Health Budget	HIV/AIDS Budget	HIV/AIDS Budget as a Percentage of Overall Health Budget
2000	1,210,993	20,000	1.65
2001	200,000	13,000*	6.50
2002	Not available	11,000	Not available
2003	Not available	9,300	Not available

*co-shared with the Philippine National AIDS Council (PNAC); In Philippine Pesos (in thousands)
(Source: Philippines National AIDS Council)

[48] Philippine Peso (exchange rate to US$ is approx. 56 Philippine peso for 1 US$.

The health budget is managed and administered by the Philippine Department of Health. At present, the organization has six main health clusters; each of which has more than 10 programs. The National AIDS and STI Prevention and Control Program (NASPC) is under the Health Development Program Cluster which monitors infectious diseases in the country. Thus, the NASPC (and the PNAC) will need to compete with other programs of the cluster for allocation.

Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM)

The Philippine government submitted a proposal to the Global Fund in 2003. The proposal entitled "Accelerating STI and HIV/AIDS Prevention and Care Through Intensified Delivery of Services to Vulnerable Groups and People Living with HIV/AIDS in Strategic Areas in the Philippines" was subsequently approved. The total funding request was for more than US $5.5 million for five years starting 2003.

Barriers and Challenges

Funding for HIV/AIDS in the Philippines, like elsewhere in the region, is still inadequate. For sustained initiatives and to stem the tide of infection, the government must provide greater allocation to AIDS. Unfortunately, there are other developmental issues that get precedence over AIDS in the country due to the relatively small official figures of those infected.

Ukraine

The in-country study could not find any evidence of increase in government allocation for HIV/AIDS. The Government has marginally increased financing of ARV treatment, but an essential increase of financing overall has not taken place. The government has thus not fulfilled its commitments in line with the DoC.

National Expenditure on AIDS

TABLE 8: Government Budget Funding in Ukraine (2000-2003)

YEAR	Purpose of Funds	Amount Allocated by Government Budget	Real Expenditure Funding (as an approx. percentage)
2000	Total to HIV/AIDS	$ 0, 933 mln. UAH[49]	100
2001	1. NAP Implementation	10,1 mln UAH	62
	1.1. Purchases of test systems for HIV tests on donor blood	8,2 mln UAH	
	1.2. Purchases of medications for PLWH treatment	1,9 mln UAH	
	2. Social assistance payments to HIV-positive children	0,6 mln UAH	67
2002	1. NAP implementation	14,3 mln UAH	60%
	2. Social assistance payments to HIV-positive children	0,7 mln UAH	91%
2003	1. NAP Implementation	12,8 mln UAH	
	2. Social assistance payments to HIV-positive children	0,9 mln UAH	Financed 100% as of September 30

(Source: UNDP 2003 Report)

To fight HIV/AIDS in 2002, 9.3 million UAH (approx. US $1.8 million) were used out of the national budget and 15.78 million UAH (approx US $2.98 million) of local budget funds.

TABLE 9: Percent of National Budget Devoted to HIV/AIDS Programs in Ukraine (2002-2004)

Year	HIV/AIDS Expenses as per National Budget (In thousands UAH)	Total Expenses as per National Budget (thousands, UAH)	Percentage of HIV/AIDS Expenses to the Total Expenses
2002	15 008,6	49 498 467,3	0,03032
2003	13 664,50	55 907 506	0,02444
2004	14 852,2	64 192 219	0,02314

[49] Ukraine Hryvnia (exchange rate to US$ is approx. 5.33 UAH per 1US$).

It is also important to mention that in the budgets of 2002-2004 there is a common budget line allocation to AIDS and Tuberculosis which means some additional spending for HIV/AIDS. In the budget for 2004 for the first time the total amount of funds (40.6093 million UAH; approx. US $7.7 million) devoted to HIV/AIDS is outlined. From the budget it is impossible to find out how much of the devoted funds will be spent on administration and organization and how much will be spent on program activities and purchasing of supplies and medication.

The national budget expenditures planned for 2004 are 64,192219 billion UAH (US $12.1 billion), out of which 40,6093 million UAH (US $7.6 million) are to be spent on HIV/AIDS prevention and treatment (Budget 2004). Out of these funds the National AIDS Program is budgeted at 14 852,2 thousand UAH (US $2.8 million).

Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM)

The Government of Ukraine has received the first portion of funding from the Global Fund. The primary purpose of these funds is the extension of medical support for HIV-infected people, strengthening national diagnosis and medical base, care and support of PLWHA. In Ukraine, US $92 million was allocated for a five- year project. Payments are to be allocated for two years with further approval in view of program efficiency. The first portion was intended to finance medical treatment of 4000 HIV-infected patients by the end of 2003.

NGOs play an active part in the decision-making processes of the Global Fund project implementation due to their participation in the CCM. For the first time in Ukraine such a structure has been created on the base of a rather large representation of non-governmental structures. Out of 45 seats the CCM reserves three seats for PLWHA, five seats for community and charitable organizations, two seats for private sector representatives, five seats for the education sector, ten seats for international organizations and twenty seats for the government.

The International HIV/AIDS Alliance was appointed temporary principal recipient to administer funds for the Global Fund program in Ukraine. The agreement is for over US $15 million and will run for a term of 12 months. The Alliance was asked to take on this role by the Global Fund Secretariat after the latter announced its decision to suspend the three existing principal recipients 'due to serious reservations over management issues'. The four areas covered by the agreement are: treatment, care and support of PLWHA; a general risk reduction campaign; targeted prevention programs for high-risk populations; and monitoring and evaluation. The program also aims to significantly expand the number of people receiving treatment from around 100 to 2100 within a year.[50]

The All-Ukrainian Network of PLWHA and SAAPF (Substance Abuse and AIDS Prevention Foundation) were involved in the process of writing the funding proposal to the Global Fund. The All-Ukrainian Network of PLWHA jointly with its partner NGOs is implementing the care and support component of the Global Fund Program.

[50] http://www.aidsalliance.org/eng/

Venezuela

The granting of financial resources to fight HIV/AIDS in Venezuela has traditionally been the main role of the State, which has managed approximately 93 percent of the allocated resources, while civil society has had a 7 percent share.

TABLE 10: National Expenditure on AIDS in Venezuela (2001-2003)

Year	Total Budget (MM of Bs.)*	Public Expenditure for AIDS** (MM of VEB)	Percentage
2001	232143030	44918	0.019
2002	264431293	67106	0.025
2003	41600.426,6	65121***	0.015

*National Budgets - National Budget Bureau ONAPRE

**Public Expenditure for AIDS includes those of the central government, the regional governments and the Venezuelan Institute for Social Security (IVSS)

***As it was not possible to gather information about IVSS´ budgetary plan for the current year, a historic projection was used

(Source: SIDALAC-MHSD)

During 2003, far from increasing financial contributions to HIV/AIDS programs, as indicated in the UNGASS Declaration of Commitment, the Venezuelan government has reduced its allocation. Likewise, it has diminished its allocation of resources to Venezuelan NGOs that work on HIV/AIDS programs.

Civil Society Funding for HIV/AIDS Initiatives

There were several direct contributions from transnational companies to Venezuelan NGOs. For example, Merck Sharp & Dohme, donated US $15, 000 to cover operational expenses of the 'Foundation Friends for Life'. Merck also contributed US $40, 000 for the implementation of the Program ‘Enterprises Respond to HIV/AIDS’, in the year 2002, managed by Acción Solidaria.

Adequate resources are critical for responding to the AIDS pandemic at the national level. This was recognized in the DoC and all governments committed to increase and prioritize national budgetary allocations for HIV/AIDS programs and ensure sufficient allocations from all relevant ministries. However, the study brought into sharp focus the resource gaps that exist at the country level for addressing issues related to HIV/AIDS. Unfortunately, none of the four governments have increased their health allocations when compared to the overall budget. In some cases the allocation has even gone down as other developmental issues get greater priority. This is particularly significant especially since without adequate financial resources none of the other commitments can be fulfilled.

Key Recommendations

- All national governments should make a needs assessment of essential public services and allocate funds accordingly. Further allocation must be based on program priorities. Funds should be managed in a transparent manner and include public monitoring of the use of government funds allocated to HIV/AIDS.

- A criteria for allocation of AIDS funds to civil society organization must be developed. This must include the setting up of effective funding mechanisms for frontline organizations; especially those delivering HIV/AIDS related services.

Lessons Learned:

- Governments are allocating fewer resources to HIV/AIDS than what is needed to control the epidemic.
- For an effective response to the AIDS pandemic, adequate resources need to be allocated to civil society for program delivery.

Civil Society Participation

Civil society has been very active since the early days of the epidemic, often taking a leading role in advocating for the needs and rights of the most marginalized and vulnerable communities. Also, civil society has an active role to play in the implementation of the DoC. The DoC in fact recognizes that implementation of the commitments is a government-led process with active civil society participation. Given the magnitude of the challenge, no one organization can respond to HIV/AIDS in isolation; rather the pandemic requires collaboration and effective partnerships to be forged for an effective and efficient response.

“We recognize and express our appreciation to those who have led the effort to raise awareness of the HIV/AIDS epidemic and to deal with its complex challenges. We look forward to strong leadership by governments, and concerted efforts with full and active participation of the United Nations, the entire multilateral system, civil society, the business community and the private sector.”

-Keeping the Promise: Summary of the Declaration of Commitment on HIV/AIDS

For this project, ICASO tried to evaluate the extent to which civil society organizations are made active partners in the implementation of the DoC by national governments in the four countries under study and what is civil society doing towards fulfilling the commitments. The results from the project indicated that though a large number of NGOs are already delivering services and are engaged in advocacy work to reverse the effects of the pandemic, awareness of the DoC among civil society is very limited. Some encouraging measures have been taken by governments for a greater involvement of civil society in the implementation of the DoC, but it is difficult to say if these have been a result of the DoC or due to the advocacy efforts of civil society. For example, NGOs representing PLWHA within individual countries have been mounting efforts to increase access to ARVs using arguments based on the right to health.[51] These actions have involved litigation in national courts, like in Venezuela, in which PLWHA argue that the government's failure to provide treatment is a violation of basic human rights.

NGO activism is important, but the active involvement of the government is critical and crucial to improving the situation. As found in the four national reports, civil society organizations are taking it upon themselves to deliver services that must be delivered by the government. Given the lack of action of the public sector, civil society has been challenged, to deliver services, to implement programs and, most importantly, to advocate for change.

[51] The International Guidelines on HIV/AIDS and Human Rights: How are they being used and applied? ICASO, 2002.

Kenya

Initiatives taken by the Government

The preparation of policy documents and strategies in Kenya draws expertise from individual specialists in different areas. Civil society input is mainly obtained through workshops and informal methods such as interviews and questionnaires. All the CSOs that participated in this pilot were of the opinion that this input was not sufficient, especially since only a small number of organizations in the country were being involved in the process.

Regarding monitoring, periodic national reviews of progress achieved in implementing the DoC are usually conducted through workshops and informal methods such as interviews and questionnaires sent to a number of identified organizations. Key civil society representatives are generally invited to take part in this process, but most CSOs are not aware of these reviews. This can be partly attributed to poor information dissemination on the part of the government and other relevant bodies. For instance, most of the participants in this study were not even aware of the existence of the DoC. Knowledge of the DoC is limited to international and national NGOs.

Some positive measures taken by the government include the creation of the National AIDS Control Committee (NACC) with networks to the community level, which is indicative of the government's commitment to fight the pandemic in partnership with civil society. However, what cannot be ascertained is how far this was a result of the DoC. NACC coordinates the efforts of NGOs, CBOs, and other stakeholders to avoid duplication and increase effectiveness. Some CSOs indicated that they partnered with the government in undertaking some if not all of their activities.

Civil Society Response

Civil society in Kenya has been actively involved in responding to the AIDS pandemic by addressing the needs of the community in their programs related to care and support, AIDS orphans, youth and other areas.

Faith Based Organizations

The World Council of Churches (WCC), has entered into partnerships with key church organizations in Kenya for a more effective response to the epidemic. The WCC has held a series of training workshops with different church groups. Individual religious organizations have also been actively involved in HIV/AIDS prevention activities and in some cases have partnered with the government for service delivery.

Pathfinder, has developed in partnership with other NGOs, a comprehensive Prevention of Mother to Child Transmission (PMTCT) project that is being piloted in three Kenyan provinces and will expand to all the eight provinces by the end of the project. The project centers on a range of interventions at the community level that will reduce vertical transmission. In this project, the efforts of community health workers is essential to create demand for services, identify potential PMTCT cases, provide referrals and raise awareness about HIV prevention.

Private Sector

In 2000, the Federation of Kenyan Employers (FKE) issued its code of conduct on HIV/AIDS in the workplace. The same year it was designated by the NACC as the focal point to address AIDS in the workplace. Since then, the Federation has set up a broad-based HIV/AIDS advisory committee to implement the FKE AIDS Education Program. It has also incorporated HIV/AIDS prevention and management into regular training activities. The private sector also, through the Kenya HIV/AIDS Business Council has played a major role in designing prevention programs in the workplace and financing interventions for care and support, restructuring medical and retirement benefits, and working with other relevant bodies to develop workplace policies related to HIV/AIDS.

Media

The media plays a critical role in reducing stigma by airing educational programs on television and radio. Additionally, they are also engaged in condom promotion mainly through the marketing of branded condoms. Most of the programs related to social marketing of condoms are donor supported. NACC also plays a key role in financing and promoting advocacy programs and awareness campaigns on prevention activities especially condom use through the media.

Philippines

Initiatives taken by the Government

In 1998, the Philippine National AIDS Council (PNAC) was reconstituted to ensure multi-sectoral representation in its governing body. In 2002, it developed the Medium Term Plan (MTP) (2002-2004) for accelerating the response to HIV/AIDS, which highlights that multi-sectoral involvement has been at the core of the national response to HIV/AIDS.

The MTP has put a structure in place for the participation of civil society in programs and projects that address the issues around HIV/AIDS. Approximately 40 NGOs in the Philippines are working together to widen the reach of their HIV/AIDS programs and to ensure the sustainability of their efforts. It is difficult to assess if these initiatives were due to the DoC.

“The Plan was developed for not just national governments, but local government; not just government but also civil society; not just organized groups, but also communities; not just institutions but also individuals.”

– 2003 Progress Report to UNAIDS

The government has partnered with the business sector in the implementation of the National Workplace Action Plan on HIV/AIDS and STD. This has been made possible by incorporating STD services into the package of company medical facilities. The Department of Labor and Employment coordinates private sector prevention efforts.

Civil Society Response

Several NGOs have initiated training and educational programs for the workplace. In 2003, about 8,000 workers, including seafarers, domestic household helpers and entertainers were trained by PAFPI in nine months. In addition, the AIDS Society of the Philippines designed a project titled ‘Menu of Partnership Options’ in collaboration with UNAIDS, and the International Labor Organization. This ‘Menu’ can be used to initiate partnerships between government/NGOs and the business sector in HIV/AIDS prevention, care and support programs. Civil society has also been involved in condom promotion. DKT, a non-governmental agency, has undertaken the distribution of condoms through its social marketing program.

The Philippine HIV/AIDS NGO Support Program (PHANSuP) acts as the training arm of the PNAC for advocacy on the National AIDS Law. Other advocacy work in collaboration with NGOs resulted in the Government Service Insurance System and Social Security System providing benefits for Overseas Filipino Workers with HIV/AIDS. PHANSuP has also undertaken skills development for various NGOs in prevention, care and support activities.

Ukraine

Initiatives taken by the Government

The strategic plan of the National AIDS Program (NAP) was developed by the MoH in consultation with members of civil society and international organizations including UNAIDS. This was done mainly through a series of special workshops and round tables prior to the preparation of the strategic plan. Though formally civil society has been involved in developing this strategic plan, the interviewees in the study, expressed a concern that consultations were made only with selected organizations and that there was a lack of transparency in the selection process. It is also not clear how the inputs from civil society are taken into account or why some of their proposals are not considered. There is lack of coordination and no mechanism is in place to take into account the opinions, comments and needs of civil society.

"... in addition to the program itself, the Plan should include an implementation strategy, expressed simply and comprehensibly. This is necessary for regional organizations to work effectively. The involvement of regional non-governmental organizations in monitoring program implementation along with the government would allow greater objectivity in the evaluation."
– NGO representative

There are also certain legislative barriers that do not allow representatives of NGOs to participate in government programs. For example, NGOs can receive funding from international donors, private sponsors, and humanitarian sources but there are no mechanisms by which the state can transfer a part of its budget for implementation of government-sponsored programs by NGOs.

Civil Society Response

Civil society organizations have been extensively involved in information dissemination and promotion of IEC materials on HIV/AIDS. The AIDS Federation East West (AFEW) developed a Solidarity Campaign with PLWHA in the mass media and designed promotional and educational materials for the campaign. The educational materials share similar images and a single slogan 'You should know more about HIV and AIDS'. The campaign was launched in March, 2000 in Kiev and lasted one year. It was later expanded to other regions. The campaign was developed and prepared in collaboration with the government and was funded by Médecins Sans Frontières (MSF).

Faith Based Organizations

The Church has some regional AIDS projects that are implemented throughout parishes together with local administrations and NGOs. Church representatives noted that there are positive changes in the government's attitude and that their social interventions are being supported by the state.

Media

Members of the All-Ukrainian Network of PLWHA were the first to speak openly in the media about their HIV status, thus giving a human angle to the HIV/AIDS problem in order to change existing stereotypes. The PLWHA Network successfully promoted participation of an HIV+ woman in a TV program titled 'Without taboos' on a major Ukrainian TV channel.

Venezuela

Initiatives taken by the Government

Civil society organizations were involved in the setting up of the National AIDS Program. However, although this was done in 2002, it was not due to the adoption of the DoC, but from a prior national commitment.

Community sector participation in all decision-making processes related to planning, execution and specifically policy for public health institutions is stated as a right and duty in Article 84 of the Constitution. However, this right is violated by public officers who avoid community participation in HIV/AIDS policy-making despite repeated requests.

Global Fund Proposal

Representatives of different government organizations, the National AIDS Program, NGOs working on HIV/AIDS and Tuberculosis, PLWHA, health workers and multilateral agencies gathered during 2002 in order to agree upon and prepare a draft country proposal to be submitted to the Global Fund. The proposal was rejected in the first two rounds.

Civil Society Response

Civil society, including PLWHA, has always acted as a watchdog monitoring the State's response regarding access to treatment and support for PLWHA. In case of irregularities, advocacy actions are carried out by CSOs to defend human rights, such as meetings with the Ministry of Health (or other authorities), organizing street protests. Also, the media has been used on a number of occasions to highlight human rights violations.

Acción Ciudadana Contra el SIDA (ACCSI), compiled a list of the commitments in the DoC and sent this with a letter to the Ministry of Health (MoH) holding the Government responsible to develop a work plan to implement the commitments in line with its obligation. Recognizing that implementation of the DoC is a government-led process, with active civil society participation, ACCSI offered to assist the MoH to design strategies to meet the targets contained in the DoC. As a result the MoH invited the NGO sector to submit projects that would complement the existing national strategic plan on HIV/AIDS and enable Venezuela to meet at least some of the commitments.

Most HIV prevention programs in Venezuela have been carried out by NGOs since the early days of the epidemic. Some of the organizations involved in HIV/AIDS community assistance services are ACCSI, Amigos de la vida, Acción Solidaria Aid for Aids, AMARE, A Vencer, Proyecto de Vida.

Pharmaceutical companies have also played a role in helping meet the targets outlined in the DoC reducing prices by as much as 70 percent. The pharmaceutical industry has also made financial contributions to the fight against HIV/AIDS in Venezuela by supporting key events such as education, capacity building and training programs.

The National AIDS Program supplies condoms to different NGOs upon request for their prevention programs. Even though there is a lack of cooperation between Government and NGOs for an effective national response to HIV prevention, in 2002, the National AIDS Program financially supported 34 projects managed by NGOs related to HIV/AIDS prevention and training.

It is important to point out that civil society and specially PLWHA have been instrumental in initiating legal actions to enforce legal provisions for accessing ARV treatment and for following up on human rights violations of PLWHA, and their communities.

Civil Society Organizations (CSOs) have been in the vanguard of the movement to curb HIV/AIDS and a crucial force in preventive education, advocacy for access to ARV/ART and the provision of direct services in treatment, care and support for the infected and affected. CSOs complement and strengthen the work of government departments and are increasingly building partnerships with private sector organizations and agencies to ensure that health and social services reach those most vulnerable, marginalized and excluded. NGOs and CBOs have lead the way in demanding the full realization of the human rights of PLWHA and vulnerable groups including relatively high standards of health care, access to other factors of survival, protection and development, and to be free from stigma and discrimination for themselves and their families.[52] However, in spite of their active role since the early days of the epidemic, CSOs involvement has been mainly in delivering programs. In none of the countries that ICASO studied, has civil society been involved in any meaningful way to monitor progress or even in decision-making. The questions that needs to be asked is why is civil society not involved in developing AIDS policies apart from the token representation on some national AIDS bodies? Or, in monitoring and evaluating progress made in meeting the DoC targets? Why are governments perceived as not transparent and accountable to the communities in reporting on the national progress in implementing the DoC targets?

Key Recommendations

- Civil society actors need to be legitimately involved in all processes including monitoring and evaluation (M&E) in order to have an impact on the response. This will require skills building and training programs to improve their capacity in M&E processes.

- It is impossible to expect that governments will monitor and evaluate the implementation of their commitments in a fair manner. A solution is to set up national M&E task forces with adequate representation from diverse civil society players.

- Strong partnerships among community players, NGOs, businesses and other sectors need to be integrated for any effective response to the HIV/AIDS pandemic.

- There is a need for better information dissemination on the DoC, not only to civil society organizations, but also to government officials. Civil society must continue to advocate to their governments and pressure them to fulfill their commitments.

- The NGO community should be involved in all decision-making processes. Concomitantly, it is incumbent upon NGOs to identify decision-making opportunities and equip themselves to effectively represent their constituencies and communities. They would need to intensify their advocacy efforts and bring to the forefront current and new issues in the changing HIV/AIDS environment. Some of these issues include: resource allocation, greater civil society participation in policies and programs, coordination of multi-faceted initiatives, improved integration between HIV/AIDS and other development issues, and at the core of it all, serve the best interest of those infected and affected.

Lessons Learned:

- There is often a considerable gap between writing good policies and implementing those policies. Hence, civil society needs to be vigilant and constantly remind governments of their commitments.
- Awareness about the DoC is low among civil society players and hence, advocacy directed towards monitoring governments' response to the targets in the DoC is limited.

[52] The NGO Community, a Leader or Follower in the HIV/AIDS Response (draft paper), ICASO, 2004.

CONCLUSION

Civil society has been at the forefront of all responses since the onset of the AIDS pandemic. After twenty years of struggle it is clearer that strong political will at all levels is important but even more important is open public debate and involvement of all stakeholders including PLWHA. Ownership and participation are vital. No single organization or institution can respond to HIV/AIDS in isolation, given the diversity and complexity of the needs that it creates. The pandemic demands mobilization, collaboration and leadership at local, national and international levels.

This became even more obvious from this project that ICASO undertook. While it was realized that governments have taken a number of measures, mainly at a policy level, to curb the spread and impact of HIV/AIDS these are by no means sufficient. Also, a critical aspect that needs to be asked is how much of these policies are actually having an impact in reducing the mortality and morbidity associated with HIV/AIDS.

Government leadership in spite of the adoption of the DoC has not been strong enough to reverse the epidemic. In fact since the adoption of the DoC, the HIV/AIDS epidemic has worsened and become more widespread. This makes one wonder that if governments are fulfilling the commitments outlined in the Declaration as they have reported to UNAIDS, then why are infection rates not going down? Some of the reasons for these are reflected in the key findings from the research as follows:

Access to Treatment: Over three years have elapsed since the DoC was adopted and yet globally only 5 percent of those in need of treatment have access to it. This study indicated that though some policies have been instituted, these are yet to be implemented. For example, to tackle the issue of drug prices, policies have been put into place for allowing the importation of generics; also, negotiations with pharmaceutical companies have been undertaken but these have had little effect in bringing down the prices of drugs substantially. The prohibitive cost of ARVs continues to be a major barrier to access. None of the countries that were studied have a comprehensive treatment plan. Without such a plan, it is impossible to implement an effective and universal treatment program. Further, poor health infrastructure continues to plague developing countries. Also in countries where access has improved, it is confined to only some urban centers. Private insurance schemes for medical care are underdeveloped in all the countries that were studied. Even when treatment is available, access is hindered because of poor information dissemination of treatment options available to PLWHA. This study confirmed that though providing treatment is primarily the responsibility of the government, in most cases PLWHA were accessing it through the assistance of NGOs and CBOs.

Empowerment of Women: This area has been one of the most neglected in terms of governmental response. Women's issues in general and specifically those related to HIV/AIDS continue to be marked by silence and denial. However, following the enormous rise in the number of women infected (fifty percent globally) and to some extent the adoption of the DoC, governments have recognized that empowerment of women is critical to stem the pandemic. Nevertheless, the research indicated that practically no targeted measures have been taken towards reducing women's vulnerability to HIV/AIDS. Most initiatives at the country level target the most vulnerable groups but invariably leave out women in the general population. The project was unable to find any instances of effective outreach programs implemented by the

government that would inform women of the risks associated with unprotected sex or generate awareness about the female condom. Nor could examples be found of specific initiatives that have been undertaken to empower women economically. In all the countries studied, there was a lack of information dissemination for the promotion of safe and responsible sexual behavior. Also, very little has been done to strengthen public sector health programs that focus on the needs of women.

Human Rights of PLWHA and other Vulnerable Groups: From the study, it is difficult to assess if the few initiatives taken by governments related to human rights and HIV/AIDS have been the result of the adoption of the DoC. Since the early days of the epidemic it has been known that the respect of human rights of all persons is integral to any response to HIV/AIDS. However, twenty years into the epidemic, and even three years after the adoption of the DoC, PLWHA and vulnerable groups continue to face stigma and discrimination that hinders their access to HIV/AIDS related services. The study results indicated that although some legislations have been adopted there has been no impact. PLWHA and other vulnerable groups continue to face discrimination and their human rights continue to be violated; whether this be related to confidentiality or loss of employment based on HIV status or access to treatment. Governments in most cases have failed to meet their international obligations as outlined in the various treaties and conventions when it comes to respecting, protecting and fulfilling the human rights of PLWHA and other vulnerable groups as they continue to be marginalized and discriminated against in the provision of all HIV/AIDS related services.

Resource Allocation: Adequate resources are critical for responding to the AIDS pandemic at the national level. This was recognized in the DoC and all governments committed to increase and prioritize national budgetary allocations for HIV/AIDS programs and ensure sufficient allocations. However, the study brought into sharp focus the resource gaps that exist at the country level for addressing issues related to HIV/AIDS. Unfortunately, none of the four governments have increased their health allocations when compared to the overall budget. In some cases the allocation has even gone down as other developmental issues get greater priority. This is particularly significant especially since without adequate resources none of the other commitments can be fulfilled.

Civil Society Involvement: NGOs and CBOs offer the first line of defense in addressing HIV/AIDS due to their flexibility and proximity to the most vulnerable communities including those not reached or intrinsically excluded by mainstream services. They have assumed a vital role as catalysts for social change through efforts to empower people who face various forms of socially-sanctioned violations. NGOs and CBOs have maintained contact and trust among the most marginalized populations such as IDUs, sex workers and migrants, who often evade the reach of government agencies. NGOs and CBOs have provided direct service delivery for care, treatment and other services together with or in parallel to government services. They have been at the forefront and have carried a leadership role in community mobilization, participation and support for local and national level programs against HIV/AIDS. They bring to policy discussions an array of frontline experiences of individuals and communities. Because of their proximity to the ground realities and their reach to the most excluded groups, NGOs and CBOs are in a position to monitor and demand from governments to be more accountable to their people.

NGOs are often represented on government AIDS bodies. However, often this representation is merely token and symbolic. Inputs from civil society are seldom taken into consideration and there is lack of transparency in the selection of CSOs that are invited. This gap is particularly glaring when questions of monitoring governments' progress comes up. Monitoring and evaluation of national activities and progress remains a major challenge for civil society because of a denial by governments to get involved in any meaningful way and also due to the limited capacity and resources of CBOs and NGOs to participate in M&E processes.

RECOMMENDATIONS

What has become clear from the pilot study is that though some legislative measures as well as programmatic approaches have been taken, there is no evidence to indicate that the governments' actions have been a direct result of the adoption of the DoC. Often policies are adopted but these are seldom implemented and have done little to alleviate the impact of HIV/AIDS on those infected and affected. The fact that policies are adopted but rarely implemented suggests that governments continue to lack political will and in some cases lack the financial resources to implement their policies. In most cases it is a combination of these two factors. Thus, civil society has a crucial role to play in ensuring that commitments made are translated into actions. In order to better implement the commitments, ICASO recommends the following strategies:

Partnerships between Government and Civil Society: Governments must engage NGOs and CBOs in national and local decision-making processes and not merely provide for their token presence on different governmental bodies. Further, governments must forge effective partnerships with civil society for the design and implementation of policies and programs for fulfilling the commitments in the DoC. Similarly, civil society too has an obligation to identify opportunities to participate and to equip themselves to effectively present and discuss their issues and agendas.

M&E Task Force: Governments should set up a monitoring and evaluation task force with adequate resources and representation from civil society to evaluate the implementation of the policies and programs adopted by the government in line with the DoC. One of the responsibilities of the task force would be to ensure that funds allocated are channeled for the right use.

Training and Capacity Building: Governments and civil society must engage in better dissemination of information related to the DoC, including its monitoring and evaluation. This can be done through capacity building and training programs for all those playing a role in policy and decision-making on HIV/AIDS. Further, organizations such as UNAIDS and ICASO must engage national NGOs and CBOs to enhance their M&E capacities so that they are better equipped to monitor the implementation of the DoC and advocate for the fulfillment of the commitments.

Review of the Indicators: UNAIDS must revisit and review its indicators for monitoring the implementation of the DoC and measuring government progress. One of the major learning from this project was that the indicators developed by UNAIDS do not measure implemen-

tation of policies but rather simply their adoption. UNAIDS must consider developing new indicators with civil society inputs that allows civil society to report on governments progress in implementing the DoC. Also, these indicators should be more relevant to the country's situation and be of greater use in program planning and policy formulation.

NEXT STEPS

The results from this pilot study clearly indicates that it is difficult to gauge the actual impact that the DoC has had at the country level. Even when governments have actually adopted policies and enacted legislation in line with the DoC, we cannot claim with certainty if these have been the result of the adoption of the DoC or rather the result of advocacy efforts by civil societies. Nevertheless, it is critical to continue to raise awareness of civil society on the DoC and to increase their capacity in monitoring and evaluation so that there is greater transparency on the measures and initiatives taken by governments towards meeting the DoC targets.

In 2004 and 2005, ICASO will extend this project to include up to 20 countries to monitor governments' implementation of the DoC from an independent lens and will continue to build the capacity of civil society. However, ICASO does realize that the pilot project was extremely ambitious in trying to examine five commitments given the time and resource constraints. Hence, in the next phase the number of commitments being studied will be reviewed so that the areas can be monitored more thoroughly within the given time and with limited resources.

APPENDICES

Appendix A – In-country Implementing Agencies & Research Teams

Kenya

Implementing Agency: Kenya AIDS NGOs Consortium (KANCO)
Project Coordinator: Allan Ragi

Research Team
Henry Kilonzo
Beatrice Ogutu
Samuel Buru

Philippines

Implementing Agency: Center for Multidisciplinary Studies on Health and Development (CEMSHAD)

Research Team:
Nymia P. Simbulan
Reynaldo H. Imperial
Laufred I. Hernandez

Ukraine

Implementing Agency: International HIV/AIDS Alliance
Project Coordinator: Andriy Klepikov

Research Team:
Pavlo Smyrnov
Hanna Dovbah
Natalya Kharchenko
Tatyana Petrenko
Yevgeniya Polshchikova
Svetlana Omelchenko
Yevgeniy Ilenko
Olga Redko
Irina Ippolitova
Tatyana Pyaskovskaya

Venezuela

Implementing Agency: Accion Ciudadana Contre el SIDA (ACCSI)
Project Coordinator: Leoncio Barrios

Research Team:
Alirio Aguilera
Sergio Guzmán
Ornella García
Alberto Nieves
Feliciano Reyna

Appendix B – In-country Organizations from Whom Data & Information were Gleaned for the National Reports

Kenya

1. Government of Kenya with all its relevant ministries and bodies
2. Civil Society Organizations: local and international NGOs, CBOs and faith based organizations working on HIV/AIDS related issues
3. Members of vulnerable groups (PLWAs, MSM, IDUs, Sex workers, confined persons) and their networks
4. Private sector
5. UN agencies

Philippines

The government agencies and institutions engaged in the study were the following:

1. Department of Health - Philippine National AIDS Council (DOH-PNAC)
2. Department of Labor & Employment - Occupational Safety & Health Center (DOLE-OHSC)
3. Department of Interior and Local Government (DILG)
4. Philippine National Police (PNP)
5. Commission on Human Rights (CHR)

Civil society groups that participated in the study were the following:

1. Remedios AIDS Foundation
2. The Library Foundation (TLF)
3. Foundation for Adolescent Development, Inc. (FAD)
4. Alternative Law Research and Development Center Inc. (Alterlaw)
5. AIDS Society of the Philippines (ASP)
6. Kamalayan
7. ACHIEVE
8. Women's Education, Development and Productivity, Research and Advocacy Organization (WEDPRO)
9. Positive Action Foundation Philippines Inc. (PAFPI)
10. Pinoy Plus

Ukraine

1. Government of Ukraine with all its relevant ministries and bodies
2. Institute of Epidemiology and Infectious Diseases
3. Editor of the social issues department, Day Newspaper
4. Pharmaceutical Company Delta Medical
5. Civil Society Organizations: All-Ukrainian Network of PLWHA, AIDS Federation East West (AFEW), Substance Abuse and AIDS Prevention Foundation (SAAPF), Ukrainian Orthodox Church, MSF, Life+, Women's Network, Club Eney

Venezuela

Director of HIV/AIDS National Program - Ministry of Health and Social Development, UNAIDS, Venezuela, ACCSI Acción Ciudadana Contra el SIDA, Instituto Venezolano de los Seguros Sociales, Office of Public Defender, Programa Nacional del SIDA-ITS, CAVINIJA de Venezuela, Lambda de Venezuela, Proyecto vida. Portuguesa, ASOVIDA. Mérida, Hospital military, AMAVIDA, RVG+, Edo. Sucre, Asovida, Mérida, AMBAR, Caracas, Sociedad Wills Wilde team, Asociación Larense de Planificación Familiar, ALAPLAF, Edo. Lara (Lara Organization for Family Planning), Casa de la Mujer Juana Ramírez, Maracay, Edo. Aragua (House for Women Juana Ramírez);, PLAFAM, Caracas; Asociación Venezolana por una Educación Sexual Alternativa (Venezuelan Associaton for Alternative Sexual Education), AVESA, Caracas; Maternidad Concepción Palacios, Caracas; Instituto Nacional de la Mujer, INAMUJER (Women National Institute), Caracas; Mujeres Unidas por la Salud (Women Joined by Health) MUSAS, Caracas; Fundación Santa Clara, Caracas; and REDPOB Coordination

Appendix C – Research Guideline To Monitor Access to Treatment

Goal: To assess progress made in expanding access to ARV therapy and treatment for opportunistic infections for PLWAs.

Information to obtain and methods:
Information can be collected from annual reports from the following bodies for each respective country:

- Kenya: National AIDS Control Council, Kenya Medical Research Institute
- Philippines: National AIDS Council
- Ukraine: Ukrainian Center for AIDS Prevention and Control, Ministry of Health
- Venezuela: National AIDS Program, Ministry of Health (Programa Nacional de SIDA).

Please collect the following information:
What HIV medication is included in your country's Essential Drug List? If you cannot find this information in a NAP report, please get a copy of the Essential Drug List from a doctor/pharmacist.

Does your country have a comprehensive policy or strategy in place to ensure or improve access to HIV/AIDS-related medicines?

If so, please note the characteristics and action plan for this strategy. How does it propose to improve access to medicines? How does it propose to make medicines affordable to all of those in need of treatment? How will these medicines be distributed, especially to vulnerable groups such as the poor, sex workers, women, men who have sex with men, prisoners, etc?

Has civil society been involved in the development and implementation of this strategy? If so, how.

Are generic drugs allowed under the law in your country? If yes, please identify the category, namely 1. manufactured in the country for internal use; 2. imported into the country for use; 3. manufactured for export only.

Please identify some of the generic ARVs. Do these include drugs to treat opportunistic infections? What is the cost of these drugs on a yearly basis for treatment?

Are there any available programs about informed choice in using ARV drugs?

Is ARV treatment provided free of cost in government hospitals? What is included in this treatment package of ARVs?

If no, what is the cost of treatment for the patient?

What are some of the barriers to rolling out/scaling up expanded access programs?

What drug regimen(s) is/are available for ARV?

Are people living with HIV/AIDS (PLWAs) treatment-literate? (i.e. are they able to make informed choices about drugs and other treatment options) Is there a program in place to ensure this? Please describe.

PLWHA

To collect information from persons living with HIV/AIDS (PLWHA), contact your AIDS Service Organization.

Ensure informed consent and confidentiality of information collected. Please ensure that the following issues are covered during the interview.

Do you have access to ARV therapy? Are you currently taking ARVs? If yes, which ones?

Are you currently undergoing other treatment? If yes, is it for opportunistic infections or for sexually transmitted diseases? What is it?

If so, how and where are you gaining access to ARV? What is the drug distribution system from which you get your drugs (e.g. how does your clinic dispense the drugs to you)? What organizations or individuals have contributed to your ability to access medications? Do these include any CBOs/ASOs?

Do you feel that you were well informed about the treatment options available to you? How was this information provided to you?

What barriers have you faced in being able to access 'effective' (in terms of access, prices, information) ARV treatment?

Has anything prevented you from accessing ARVs? If yes, what?

Has accessing a competent health care provider to provide treatment and care been a challenge?

Are the drugs prohibitively expensive and/or unavailable? If you are receiving drugs, who pays for them?

If you are being treated, has adherence to your drug regimen been a problem for you? Have you had any support to help you adhere? If yes, from where?

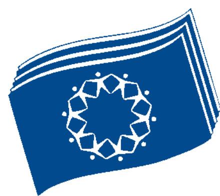
Has your health status been monitored during ARV therapy? What kinds of tests were done? Have you had to change regimens? Have you had any tests to see if you have become resistant to any of the drugs?

Please attempt to assess wherever possible through case studies, whether your government is forming partnerships with NGOs and civil society to involve them in the implementation of commitments regarding access to medications. How is civil society participating?

Please investigate if the government has been taken to court for issues related to access to HIV/AIDS treatment.

Appendix D - Comparative Analysis of Government Response to the DoC in Four Countries

	Kenya	Philippines	Ukraine	Venezuela
Access to Treatment (1) Government has adopted required policies for scale up	Yes	No	Yes	Yes, but these were adopted prior to the DoC
(2) Generic medicines	Yes	Yes	Negotiations underway	Yes, recently
(3) Negotiations with pharmaceutical companies leading to decrease in prices	Yes, on a policy level only. Prices though have come down	No. AIDS is not a priority	Yes	Negotiations halted
(4) Improved budgetary allocation for scale up	No	No	Yes, marginal	No indication
(5) Legislation	No	No	Yes, some legislation such as provision of ARVs for PMTCT	Yes, since legislation have been adopted
(6) Indication that Government responses have led to improved access	Yes. There has been a decline in the death rate since 2001	No	No, only 3 percent of those in need have access	Information not available, but no indication
Empowerment of Women (1) Government responses have led to improved access	Yes., but not implemented	Yes, prior to the adoption of the DoC	No, only related to MTCT	No, only related to MTCT
(2) Legislation	No	Yes, before DoC	No	No
(3) Female condom accessibility and awareness	No initiative yet to improve access or create awareness	Low, awareness, knowledge and acceptance	Information not available on accessibility, but low awareness	Very expensive, low awareness and acceptability
(4) Overall assessment	The response has not been adequate as clear from rising infection rates	Inadequate response	Inadequate response as most responses are targeted towards IDUs (male)	Inadequate response as most initiatives are targeted towards MSM
Human Rights (HR) (A) HR of PLWHA - policies and programs	Some legislation has been adopted, but these have not been implemented	Yes, but violations continue	Some legislation has been adopted, but these are often neglected	Legislation exists prior to adoption of DoC
Access to information	No	Partially, through some NGOs	Practically none from government sources	Some from NGOs
(B) Vulnerable Group - policies and programs	No (sex workers)	Yes, some discriminatory ones against sex workers	Some legislation only for IDUs	Policies in the Strategic Plan but no legislation
Access to Information	No, marginalized completely	Partial through NGOs	Some developed by NGOs primarily for IDUs	Yes, through NGOs
Resource Allocation (2002-03) (1) Increase in allocation	No	No	No	No
(2) Approx. percentage (%) allocation to health	4%	Less than 5%	Information not available	Information not available
(3) Percentage (%) allocation to HIV/AIDS	Information not available	Information not available	Less than 1% of total budget	Less than 1% of total budget
(4) Are NGOs represented on the CCM	Yes	Yes	Yes	Yes
Civil Society Involvement (1) National AIDS Body	Yes	Yes	Yes	Yes
(2) Government partnerships with civil society for program implementation	Yes	Yes	Yes	Yes
(3) CSO involvement in monitoring progress	Partially, invited at workshops that review progress	No	No	No



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

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