



**ANALYZING CIVIL SOCIETY PARTICIPATION
IN COUNTRY-LEVEL HIV/AIDS UNGASS 2006 REVIEWS**

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UNEP, THE UNITED NATIONS ENVIRONMENT PROGRAM

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Acronyms

AHPN	African HIV Policy Network
AIDS	Acquired Immunity Deficiency Syndrome
APCASO	Asia Pacific Council of AIDS Service Organization
ARV	Antiretroviral
CACC	Constituency AIDS Control Committees
CAPA	Center for AIDS Prevention and Promotion Alleviation Administration
CBOs	Community-based Organizations
CCM	Country Coordinating Mechanism
CDC	US Centers for Disease Control and Prevention
COC	Continuum of Care
CPN+	Cambodian People Living with HIV/AIDS Network
CRC	Convention on the Rights of the Child
CRIS	Country Report Response System
CS	Civil Society
CSI	CIVICUS Civil Society Index
CSO	Civil Society Organization
DACC	District AIDS Coordinating Committee
DFID	UK Department for International Development
DHS	Demographic Health Survey
DoC	Declaration of Commitment on HIV/AIDS
FBOs	Faith-based Organizations
FHI	Family Health International
GFATM	Global Fund against AIDS, TB and Malaria
GIPA	The Principle of Greater Involvement of People Living with or affected by HIV/AIDS
GMFA	Gay Men Fighting AIDS
GOM	Government of Malawi
HACC	HIV/AIDS Coordinating Committee
HIV	Human Immunodeficiency Virus
ICASO	International Council of AIDS Service Organizations
IDP	Internally Displaced Person
IDU	Injecting Drug User
INGO	International Non-Governmental Organization
JAPR	Joint AIDS Program Review
KANCO	Kenya AIDS NGO Consortium
KHANA	Khmer HIV/AIDS NGOs Alliance
KNASP	Kenya National HIV/AIDS Strategic Plan
LNGO	Local Non-Governmental Organization
MAP	World Bank Multi-sectoral AIDS Program
MHC	Man Health Committee
MANET+	Malawi Network of People Living with HIV/AIDS
MOPH	Department for Disease Control of the Ministry of Public Health

MDGs	Millennium Development Goals
MMM	Mondol Meth Chauy Meth
MOH	Ministry of Health
MSM	Men who have Sex with Men
MTCT	Mother-to-Child Transmission
NAA	National AIDS Authority
NAC	National AIDS Committee
NACARS	NAC Activity Report System
NACC	National AIDS Control Council
NAME	National HIV/AIDS Monitoring and Evaluation
NAPHAM	National Association of People with HIV/AIDS in Malawi
NAT	National AIDS Trust
NCHADS	National Center for HIV/AIDS, Dermatology and STDs
NGOs	Non-Government Organizations
NSF	National Strategic Framework
NSP	National Strategic Plan
OPC	Office of the President and Cabinet
OVC	Orphans and children made vulnerable by HIV/AIDS
PEPFAR	Presidential Emergency Plan for HIV/AIDS Response
PHAC	Public Health Agency of Canada
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
PPA	Program Partnership Agreement
RIPA	Real Involvement of People with AIDS
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
THT	Terrence Higgins Trust
TUC	Thailand Ministry of Public Health
TWG	Technical Working Group
UKC	United Kingdom Coalition of People Living with HIV and AIDS
UKP	United Kingdom AIDS and Human Rights Project
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session
USAID	United States Agency for International Development
VAAC	Vietnam Administration for AIDS Control
VCT	Voluntary Counseling and Testing
VUSTA	Viet Nam Union of Science and Technology Associations
WHO	World Health Organization

Executive Summary

Introduction

At the United Nations General Assembly Special Session (UNGASS) dedicated to HIV/AIDS held in June 2001, all 189 UN members adopted the Declaration of Commitment on HIV/AIDS. The Declaration 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. The inclusion of persons infected and affected is vital to ensure that government policies and actions are responsive to the needs and realities of persons living with HIV and AIDS.

The UNGASS Declaration of Commitment on HIV/AIDS (DoC) sets out concrete, time-bound commitments to ensure a comprehensive and effective global response. In particular, through Article 94 of the Declaration, countries commit to: “Conduct national periodic reviews involving the participation of civil society, particularly people living with HIV/AIDS (PLHIV), vulnerable groups and caregivers, of progress achieved in realizing these commitments; and identify problems and obstacles to achieving progress and ensure wide dissemination of the results of these reviews.”

The Declaration is a powerful tool to guide and secure action, commitment, support, and resources. With many targets set for 2005, and the UNGASS+5 meeting scheduled to be held in New York in June 2006, periodic national reviews were undertaken in late 2005. UNAIDS sent out instructions in August 2005 with a request that governments submit their country reports by 31 December, and ensure that civil society actively participate in the process.

In the past, country reports have rarely included the voices of civil society, especially vulnerable groups such as PLHIV. In many countries, civil society has not yet had the opportunity to participate in the review process to present views on government successes and failures in implementing UNGASS. While the involvement of people living with and affected by HIV has increased at national levels, the challenge is to ensure that the development and implementation of HIV and AIDS programs involve the full participation of the women, men, and young people who are most directly impacted by the disease. As a result, members of civil society are increasingly organizing to maximize opportunities to be involved in national and global reporting, and around the UNGASS review meeting in New York.¹

In consultation with other organizations working on HIV globally, CARE International commissioned a climate survey covering six countries (Cambodia, Kenya, Malawi, Thailand, United Kingdom, and Vietnam) to explore civil society experiences and document lessons learned in the country-level UNGASS 2006 national review processes. The expected outcome of the assessment included:

- ✘ Development of a questionnaire and methodology, which could be modified and used by others for documenting the ongoing process of improving civil society participation.
- ✘ An analysis of civil society participation in the national UNGASS review, especially by organizations of PLHIV and other vulnerable groups.
- ✘ Recommendations for improving participation in future national reviews.

¹ Please reference AIDS Advocacy Alert!, International Council of AIDS Service Organizations (ICASO), Issue No. 2, Dec. 2005; and the Ecumenical Advocacy Alliance for faith-based activities at <http://www.e-alliance.ch/index.jsp>.

Summary of overall findings

The diversity of factors fueling the AIDS epidemic varies in each country studied. There are also differences in the capacities of government structures, national incomes, health systems, funding levels, number of donor and development agencies, and coordination mechanisms. The climate surveys showed that there was no single approach to managing the UNGASS national review process. However, there were common findings across all countries surveyed, which helped to inform the lessons learned and recommendations.

In general, civil society interviewees concluded that they did not fully participate in the process of preparing inputs for the UNGASS reports. Though civil society has been allowed some input with regard to progress reports, **respondents in almost all of the countries felt that their involvement was *ad hoc* and merely representational.**

This was, in most cases, due to lack of capacity, rather than lack of will, on the parts of both civil society and government. In every country surveyed it was stated by both government and civil society respondents that the government authority mandated to lead the national UNGASS review process had **limited capacity**, staffing, and funding. These offices often lacked capacity for overall monitoring and evaluation (M&E) coordination, information gathering, and analysis. Therefore, UNAIDS or other international partners most often funded the consultation process, and in many instances, wrote the report. Some civil society respondents also felt that they had limited capacity to fully engage in the national review process.

The **relevance of UNGASS to some civil society organizations and governments was not clear.** Most of the people involved in the assessment knew of the UNGASS for HIV/AIDS, but there was limited understanding of the Declaration of Commitment or how it specifically related to their countries and/or programs. More than half of the civil society organizations surveyed said they had little or no awareness that a report was being prepared.

The survey found that when governments involved civil society, networks of people living with or affected by HIV/AIDS were almost always represented in the process. However, **stigma**

continues to be a barrier to civil society participation as it prevents PLHIV from being empowered and involved in UNGASS national review responses. This is especially true for the most vulnerable and marginalized populations.

One of the largest obstacles to developing the UNGASS national reports was the **lack of, or weak, national monitoring and evaluation systems.** As was the case in **Cambodia**, this made it very challenging for governments to report the achievements against the UNGASS indicators. Instead, UNGASS reporting was most often managed as a project, which came around every two years. Without the anchor of government support, efforts to harmonize and align the data gathered were not effective. While there were a number of participants involved in the UNGASS reporting and review, in reality processes were often driven by only a few people. The government office responsible for producing the national review did not always share the report with other government offices and civil society organizations providing data.

Recommendations on how to improve civil society involvement

Recommendations were provided by the government and civil society respondents as to how best improve the management of UNGASS national reviews. Several interviewees stressed the need for **building the capacity of government and civil society so the review process could be institutionalized**, and not just managed by individuals. Joint institutional capacity assessments should be supported to determine and identify capacity gaps for managing the UNGASS review. This step is critical since capacities vary greatly among government, the private sector, and civil society organizations. Strengthening civil society coalitions at the national and local levels, especially groups of PLHIV, so they may more effectively interface with local and national government entities would improve the reporting process. Thus for both government and civil society to participate effectively, greater capacity strengthening is required in areas such as advocacy, monitoring, and evaluation.

The assessment findings indicate a strong **need for education about the Declaration of Commitment**, UN processes and their relationship to national AIDS strategies. All countries

reviewed have national AIDS strategies and are working toward one monitoring framework. The relevance of the Declaration could be clarified by showing audiences how the goals have been integrated into national strategies.

Civil society organizations and most of the government respondents interviewed during the assessment were very enthusiastic about participating in the UNGASS process. However, they felt their **participation could have been more meaningful had they been involved much earlier and consistently** throughout the process. This was the case, for example, in **Kenya**, where major Nairobi-based networks contributed parts of the report. To address this issue in **Vietnam**, a mapping exercise or study on the current role and contribution of civil society in HIV/AIDS programming was recommended. This would afford the government a better understanding of what and how civil society can contribute to the national review process.

There is a strong **need for continued political commitment and leadership** at the national level. In cases where there was little or no government commitment or leadership, international partners such as UNAIDS stepped in and managed the processes. This partner support provided important assistance throughout the national process but may have limited local ownership surrounding the UNAGSS report.

The government must work with donors to create a **harmonized approach to monitoring, evaluating, and reporting**. Donors should provide support for M&E capacity strengthening and participatory methods in order to strengthen reporting and partnership between government and civil society based on the **"Three Ones" principles** (one national plan, one national coordinating body, and one national monitoring and evaluation system). Part of this effort could include building or reinforcing intersectoral and sectoral management procedures and structures to improve coordination, data collecting, and review processes. In **Malawi** the UNGASS reporting process has been integrated into the national M&E framework.

All parties need to have enough time to work together and to sufficiently consult before reaching consensus on what to include in the final report.

More time should be allowed for analyzing the information, and producing the final report – jointly owned by all stakeholders. This will **allow enough time for a transparent and participatory review**. Assigning key point persons, even where there is no formal process, will allow access to those who want to participate. Developing clear roles and job descriptions, which include communications or information sharing, is critical. Several respondents commented that the national review process helped to bridge the gap in trust between government and civil society. Promoting more **participatory approaches involving civil society with government** will encourage ownership, sustainable partnerships, and effective responses if those primarily concerned are involved throughout all stages of design, implementation, monitoring, evaluating, and reporting to ensure meaningful participation. In **Thailand**, it was suggested that a national forum for sharing information and the final report would help to build participation and partnership.

Broadening the scope of reporting in developed countries may strengthen national response and more accurately reflect the global response to HIV. In the **United Kingdom**, civil society felt there was a lack of coordination across government agencies. There was particular concern that the Department for International Development (DFID) did not participate in the UK response. The inclusion of development aid would have more accurately reflected UK contributions toward achieving UNGASS commitments.

Finally, **tools exist for engaging civil society organizations, especially PLHIV**. The Declaration of Commitment is one such tool that is being used and can be further strengthened. Two other key frameworks are useful guides for meaningful community involvement. First, the Principle of the *Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)* has been critical to ethical and effective national responses to the epidemic.² Second, *the Code of Good Practice for NGOs Responding to HIV/AIDS*, which has brought the GIPA Principle several steps forward. These frameworks will also help to inform the **development of effective communication and advocacy strategies**. With the support of donors and other local stakeholders, governments need to arrange opportunities

2 From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA), UNAIDS, 1999.

to explain the benefit of the national UNGASS reporting processes to civil society. Strategies must target specific audiences so that all AIDS stakeholders fully understand the Declaration of Commitment and have regular opportunities to provide feedback. To be effective, the application of any of these tools has to first be understood by civil society and by government.

As we undertake the five-year review of the Declaration and examine what hinders its implementation, this assessment found that the intended beneficiaries of these international commitments are not sufficiently part of the processes that affect them. Without the partnership of this community, the targets of the Declaration of Commitment cannot be met. ■

Section one

Background and Methodology

Background to the Study

This report is a part of CARE International's Africa Initiative, a project designed to increase HIV and AIDS advocacy at the international, national and local levels based on CARE's experience in the field. Participants in the Initiative have developed a vision of making people affected by HIV and AIDS central players in shaping policies and services that meet their needs and holding to account those responsible for their design and implementation. The Declaration of Commitment serves as an instrument for accountability at the national and international levels, especially in its emphasis on civil society participation in national reviews. Therefore, CARE has decided to advocate for civil society participation in national government reviews toward progress of the UNGASS Declaration of Commitment (DoC).

The global response to the AIDS pandemic is guided by the Millennium Development Goals (MDGs) and the UN General Assembly Special Session (UNGASS) on HIV/AIDS. The historic UN Special Session, held in June 2001, was the first time the General Assembly came together to discuss a public health issue. The UNGASS Declaration of Commitment on HIV/AIDS (DoC) – unanimously adopted by UN Member States – sets forth concrete, time-bound commitments to ensure a comprehensive and effective global response.

At the special session, all of the world's leaders went on record as endorsing a set of specific global targets in combating HIV/AIDS, and the formal declaration explicitly underscored the links between poverty, underdevelopment, and illiteracy with regard to the spread and impact of HIV. It also recognized that stigma, silence, discrimination, and lack of confidentiality undermined prevention and care

efforts; and that gender equality and the empowerment of women and girls were fundamental to reducing vulnerability.

Specifically, governments pledged: *"by 2003, to enact, strengthen or enforce as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social exclusion connected with the epidemic."*³

The UNGASS Declaration of Commitment for HIV/AIDS states that, *"maintaining the momentum and monitoring progress are essential."* Specific reference to the involvement of civil society is mentioned as follows:

Article 94. "Conduct national periodic reviews involving the participation of civil society, particularly people living with HIV/AIDS, vulnerable groups and caregivers, of progress achieved in realizing these commitments and identify problems and obstacles to achieving progress and ensure wide dissemination of the results of these reviews..."

UNAIDS issued national guidelines to be used for monitoring the implementation of the Declaration of Commitment on HIV/AIDS at both country and global levels. National governments were advised to refer to these guidelines in preparing their

³ United Nations General Assembly, "Declaration of Commitment on HIV/AIDS," 27 June 2001.

UNGASS reports, which were submitted to UNAIDS Headquarters at the end of 2005. National reports were expected to be completed in close collaboration with key partners from the UN system, bilateral agencies, civil society, and the private sector. The improved guidelines on the construction of core indicators included information that was used in the 2003 UNGASS reports, with a list of core indicators for different types of epidemics, and additional guidance to improve the quality of data collection.⁴

A meeting of the Steering Committee on Civil Society Participation in the UNGASS HIV/AIDS Process was held in New York on 11-13 January 2006. The members of the committee were elected from among the NGO signatories of a joint proposal to UNAIDS in early 2005. The committee's mandate is to follow-up and monitor whether clear guidelines and mechanisms for civil society participation are put into place for the preparation of national and global progress reports on implementation of the DoC. The UN General Assembly President's Office (GAPO) also requested the UNAIDS Secretariat to convene a task force of civil society representatives to help ensure the effective and active participation of civil society organizations in the UNGASS Review Meeting to be held on 31 May-2 June 2006. The task force operates through regular conference calls and meetings in New York prior to these meetings.

Two key frameworks provide a useful guide to assist with involving civil society in a meaningful way in national AIDS responses and monitoring the UNGASS processes. At the 1994 Paris AIDS Summit, 42 national governments declared that the *Principle of Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)* was critical to ethical and effective national responses to the epidemic.⁵

Completed in 2004, *The Code of Good Practice for NGOs Responding to HIV/AIDS* brought the GIPA principle several steps forward. Close to one hundred organizations worldwide have signed onto the Code. Although this is not a legally binding document, nor was it designed to apply to governments, the platform does set out a number of guiding principles, which apply a human rights approach to the range of HIV-specific health, development, and humanitarian work undertaken by NGOs responding to AIDS. These principles are embodied within good practice principles, which should guide how civil society organizations operate. The Code builds on

the UNGASS commitments and integrates aspects of GIPA into the framework to assist civil society organizations with improving the quality and cohesiveness of their work. It also provides guidance for ensuring accountability to partners and beneficiary communities.

The Declaration calls for the careful monitoring and annual reporting of progress toward implementing the commitments. As stated in Article 94, these national periodic reviews are to be completed with the participation of civil society, specifically persons living with HIV and AIDS, vulnerable groups, and caregivers. These reports are designed to identify problems and constraints and recommend action to realize the Declaration's targets.

The assessment also attempted to review if these international frameworks are being used to enable partnerships between governments and civil society. Recent events to mobilize civil society around the UNGASS process included a meeting called "Revitalizing the Global Movement – Nairobi Think Tank Meeting of People Living with HIV" on 28-30 November 2005. The purpose of this meeting was to "take GIPA to a higher level of meaningful active participation and revitalize the global movement of people living with HIV."⁶

Developing systems of accountability to ensure the meaningful participation of PLHIV was one of the key issues discussed. Therefore, applying the principles of GIPA to the management of the UNGASS review process at national levels will provide some insight into whether the support for GIPA has been translated into action and linked to the UNGASS monitoring and reporting process. The pyramid of participation included in both GIPA and the Code provides a useful guide to how civil society, specifically PLHIV, may be involved in HIV and AIDS programming and policy-making.

Conceptual framework

The primary goal for developing this climate survey was to shed light on the extent to which meaningful participation of civil society in the UNGASS review process was being achieved.

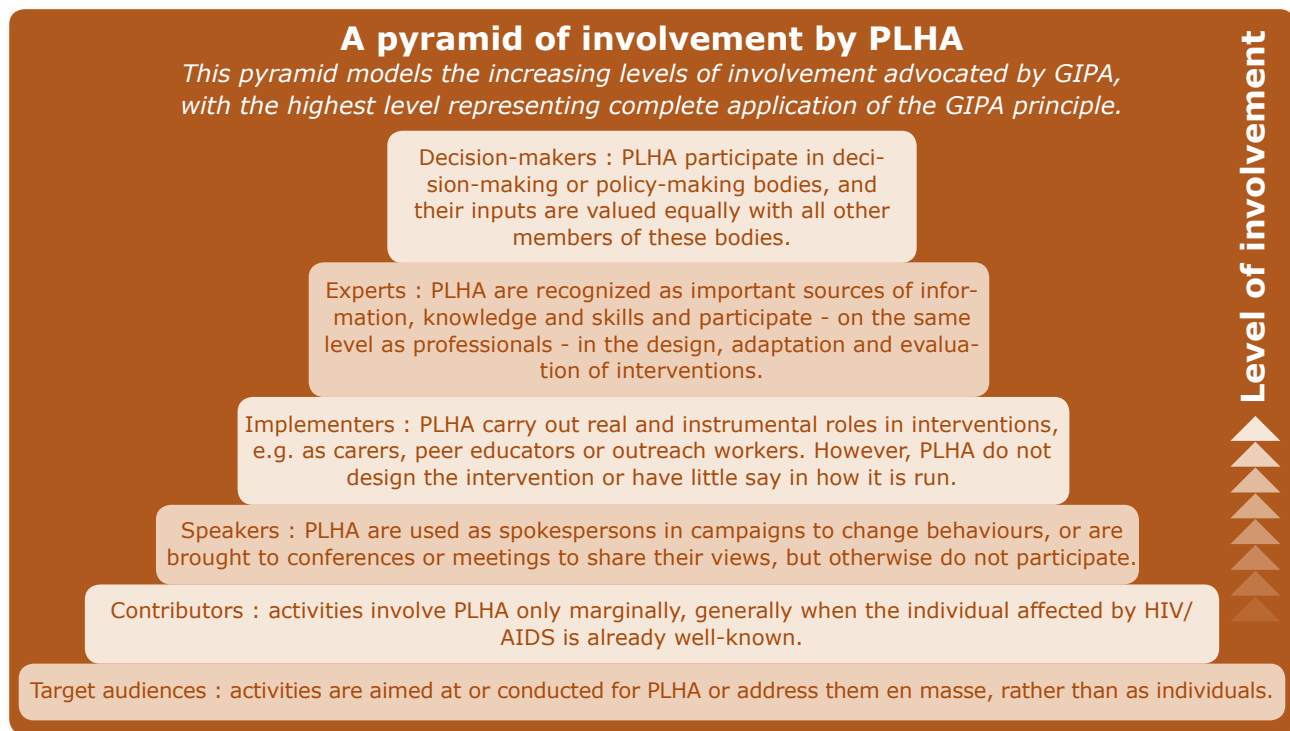
4 "Monitoring the Declaration of Commitment on HIV/AIDS, Guidelines on Construction of Core Indicators," UNAIDS, July 2005.

5 From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA), UNAIDS, 1999.

6 Statement: Nairobi Think Tank meeting of PWHA - Revitalizing the Global Movement Nairobi Think Tank meeting of people living with HIV 28-30 November 2005, AF-AIDS posting.

A pyramid of involvement by PLHA

This pyramid models the increasing levels of involvement advocated by GIPA, with the highest level representing complete application of the GIPA principle.



Adapted from *From Principles to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS*, UNAIDS 1999.

In developing the conceptual framework, CARE International consulted with Andy Seale at UNAIDS, Kieran Daly at ICASO, Allesandra Nilo at Gestospe, Helena Choi at the Open Society Institute and Ronald Kayanja at PANOS in order to coordinate efforts and discuss the assessment design. Additionally, meetings were held with Marcel Van Soest at the World AIDS Campaign, and with Francoise Welter at GNP+.

The framework and terms of reference for this climate survey were discussed at a global meeting on HIV and AIDS mobilization and advocacy in London on 5-6 February 2006. Over 60 civil society organizations were present at this meeting. An internal review also took place at CARE International with the staff participating in the global CARE International HIV/AIDS Task Force, and CARE International staff in Cambodia, Kenya, Malawi, Rwanda (originally a candidate country), Thailand, United Kingdom, and Vietnam.

Assessment methodology

The purpose of conducting the climate survey⁷ was to explore civil society experiences in the Country-Level UNGASS 2006 review processes and to document lessons learned from the experience.

The outputs for the survey include:

- ✘ Development of a questionnaire (tool) and methodology, which could be modified and used by others for documenting the ongoing process of improving civil society participation.⁸
- ✘ An analysis of the extent of civil society participation in the national UNGASS review, especially by organizations of PLHIV and concerned for people affected by AIDS.
- ✘ Recommendations for improving participation in future reviews.

Critical assumptions

The purpose of developing this climate survey methodology was not to document the implementation of the national programs. This is already being accomplished by numerous "shadow" reports mobilized by civil society consortia at global, regional, and country levels.⁹

This survey methodology builds on existing methods modified to assist with reviewing the UNGASS national review processes.¹⁰ It is also our hope that the development of this survey and report will pro-

⁷ Refer to CSAT World Bank adaptation.

⁸ See Annex 1.

⁹ These reports are available at www.ungasshiv.org along with a list of tools available for improving civil society participation.

¹⁰ Some studies and methodologies reviewed included white papers from ICASO, ICW, PANOS and Soros.

vide others with a resource to better assess the involvement of civil society in national reviews. Civil society is a complex concept. The task of identifying civil society's essential features and designing a strategy to assess its state is, in itself, a complicated process. The climate survey methodology sought to accommodate cultural variations in understandings of civil society. However, this was not always possible, as documented in the case of Vietnam. Therefore, the definition from *CIVICUS Civil Society Index (CSI)* defining civil society as "the arena, outside of the family, the state, and the market (or private sector) where people associate to advance common interests" was used in this survey.¹¹

Sampling frames

MODES OF DATA COLLECTION

Qualitative research methods were the basis for the development of this climate survey methodology. A qualitative paradigm with its holistic, inductive nature expands and continually augments information to include more possibilities, and thus enlarges, rather than narrows, the possibilities of feedback.

Consultants carried out the climate survey with government and civil society in six countries: **Cambodia, Kenya, Malawi, Thailand, United Kingdom, and Vietnam.** CARE country offices and national staff also assisted with the process. Feedback on the questionnaire was incorporated as part of the assessment so the tool could be modified based on the various national review experiences and cultural differences in each country. The methodology consisted of three areas: (A) a contextual study (desk review); (B) interviews with civil society organizations and government; and (C) community case studies.

A. Context study (desk review)

The context study was carried out by analyzing existing secondary information and documentation. This included providing a brief account of the enabling environment for civil society engagement in each country. This information helped inform the interviews conducted in-country. It also took into account existing work being done around shadow reports, the UNGASS preparation process, and the official national reports submitted to UNAIDS.¹²

B. Interviews with civil society organizations and government

The second level of analysis was conducting the survey using a questionnaire¹³ based on semi-structured one-on-one interviews with civil society organizations (targeting groups involved in the UNGASS reporting as much as possible, including PLHIV, populations most vulnerable such as IDUs, men having sex with men (MSM), migrant laborers, youth, rural communities, sex workers, etc.), and some government officials in specified ministries.

The process involved interviewing 15 to 35 individuals selected for their knowledge and experience with HIV and AIDS programming to obtain a rapid "snap shot" of their experience. Interviews were qualitative, in-depth, and semi-structured. They relied on the questionnaire and the interviewer subtly probed the informant to elicit information, opinions, and experiences. In order to protect confidentiality and ensure security, no individual responses have been identified. Alternatively, trends are identified, measured, and reported. All participants were assured that their responses would remain absolutely confidential and under the sole ownership of CARE International.

C. Community case studies

Collecting case studies in the form of project experiences is one way to document lessons learned with respect to involving civil society. The case studies highlighted some examples of best practices and lessons learned in each country where civil society actively participates in government implementation, monitoring, and reporting around UNGASS. These cases have only been cited for organizations or individuals who wished to have their information shared publicly as part of this study.

QUALITATIVE TOOLS

Qualitative data was collected to understand the process and inputs toward the UNGASS National Review processes. Written (e.g. personal anecdotes, program progress reports) and oral (e.g. interviews using questionnaire) data were collected.

A. Written/material data: Written documents, both private and public, were collected from the various government and civil society participants. These documents included, but were not limited to: national frameworks, existing reports, policies,

11 "CIVICUS Civil Society Index Summary of Conceptual Framework and Research Methodology."

12 Please reference the bibliography for the description of resources reviewed.

13 Please see Annex 1 for examples of the questionnaires.

public (written) declarations, newspaper articles, training materials, field notes, etc. Written documents from policy statements, project documents, and training materials were secondary sources.

B. Oral data: Interviews using the questionnaires were carried out with civil society and government to understand and elicit experiences with the UNGASS national review process. There were multiple dimensions to the collection of oral data ranging from brainstorming (i.e. non-directive, very unstructured and exploratory exchange) to focused discussions with an individual or group (i.e. directive, structured, and set exploratory exchange). For the sake of this survey, formal field-based interviews that were preset and somewhat directive (i.e. semi-structured) were primarily used.

QUALITY ISSUES: SAMPLING, RELIABILITY AND VALIDITY

The quality of data collection is essential to the credibility of any survey, no matter how much care is taken in design, development, planning, and analysis. There were several key reliability and validity factors that were considered and appropriate solutions planned:

A. Practical sampling: In most cases and when possible, the respondents were a cross section of the communities. The consultants tried to ensure a balance in age, gender, religious and ethnic groups. Even though each country is unique in its experiences it was important that the sampling in each country have similar themes in order to understand some of the general issues impacting participation.

As this was a rapid assessment, it was not possible to manage a large sampling. Instead, it was suggested that at **least 15 respondents (organizations/individuals) in each country** complete the questionnaire. This size allows for a snap shot of the trends instead of indicating all of the details concerning civil society participation. The following sampling was suggested (but was not limited to):

1) Government (5 individuals)

- a)** National AIDS Council or equivalent (ideally the individuals(s) responsible for preparing the UNGASS reports)
- b)** Ministry of Health (Program Policy or M&E Depts. responsible for providing information for the reports)

- c)** Minister of Gender and/or Social Development (preferably ministry responsible for gender programming and/or OVC programming)
- d)** Other sector ministries important in terms of mainstreaming HIV/AIDS (e.g. education, agriculture)

2) Civil society (10 respondents – categories a) and b) are the most important and at least 4 interviewed should be women)

- a)** Networks of people living with HIV/AIDS (ensure women's networks and youth networks were interviewed)
- b)** Organizations representing and providing programs for the most vulnerable to include sex workers, MSM, rural communities, IDUs, migrant workers, widows, refugees, etc.
- c)** INGOs
- d)** FBOs
- e)** Other CBOs
- f)** Quasi-governmental organizations
- g)** LNGOs and LNGO networks
- h)** OVC organizations
- i)** Youth groups

B. Reliability: To avoid transcription error, to the extent possible, data collection and reporting formats were linked to the questionnaire and provided to the consultants.¹⁴

C. Validity: To ensure the validity of qualitative data, information was collected from semi-structured interviews, observation worksheets, etc., and triangulated with other secondary resources. After the data was triangulated, it was cross-analyzed, (i.e. qualitative data was checked with various members of the team studying this question) to verify each data collector's interpretation of the data before it was synthesized into a final report.

Limitations of the assessment and alternative explanations

The following feedback was provided collectively from the consultants conducting the assessment over a period of almost two months. These issues should be considered if the methodology and assessment questionnaires are to be strengthened for additional assessments in the future.

- ⌘ Because this was a rapid assessment, it was often difficult to select the appropriate groups

¹⁴ These are available from the CARE International Secretariat in Brussels, Belgium upon request.

for the interviews. Consultants relied on the advice of others. Often respondents were selected in consultation with stakeholders such as local governments, DFID, USAID, UNAIDS, CARE International country offices, Family Health International, etc.

- ⌘ In some countries, there were certain limitations (e.g. competing priorities and time frame) for carrying out the survey that prevented a more in-depth understanding of the lessons learned and constraints involved with government-civil society collaboration.
- ⌘ Following the assessment, several consultants felt that the sample size was too small and did not include many key government sectors, especially in a multi-sectoral environment. Therefore, the report may not reflect a comprehensive viewpoint of the government as well as it reflects civil society's perceptions.
- ⌘ Some interviewed stated that PLHIV representatives at national-level consultations did not always represent their constituents. Other interviewees echoed the view that PLHIV currently working at the national level did not have the capacity to participate in the national review process.
- ⌘ It was difficult to obtain interviews with many vulnerable groups since the involvement of sex workers, injecting drug users, and men who have sex with men is limited, there being only a few organizations working with these vulnerable populations. Their representation was often by proxy through NGOs.
- ⌘ Feedback from the assessment process indicated there were limitations with regard to the questionnaires. Several questions were closed and there was no guideline as to how to analyze them. This may have led to the "under use" of the information collected. Many respondents were not in a position to answer some of the questions in the questionnaire because they did not know or were not involved in many aspects of the review process. The questionnaires were premised on the basis that even if an entity had not been involved in the processes of the UNGASS report, they at least knew of its existence. The survey assumed a much more detailed process and involvement of civil society in the national review process.
- ⌘ Often governments called in civil society to discuss the UNGASS as part of other meetings; therefore, reviewing "the process" as part of the assessment was a challenge in some countries.
- ⌘ All assessments were conducted in the capitals or other large cities so the findings may not have adequately described civil society and government perceptions outside of these environments. Additional surveys should be conducted to include more civil society organizations and government offices operating in peri-urban and rural areas. It is not certain if proximity to the capital improves awareness of UNGASS and the national review process, but it is assumed to make a difference.
- ⌘ An interesting issue arose in Vietnam concerning the definition of civil society organizations and participation. The lack of a common understanding about the role of civil society in Vietnam created difficulties for respondents to provide accurate answers on participation, and in turn, for the researcher to provide an accurate interpretation of the results.
- ⌘ The topic of the survey had the potential to be politically sensitive. Therefore, it required significant time for clarification and endorsement of the survey report in-country. There was a lack of guidance on how best to share the results of the survey report with concerned agencies in-country.
- ⌘ The limited time frame for conducting the field work sometimes made data collection and verification more difficult. ■

Section two

Findings and Recommendations

Contextual analyses and factors affecting involvement

The primary question asked during this climate survey was whether governments managing the UNGASS national review process fulfilled their commitments under *Article 94* of the Declaration. Article 94 implies that a *national periodic review* involving the participation of civil society should precede the compilation of a country report. The intent behind this article was that there should be an interactive process of engagement from the outset.¹⁵

Some may ask why the assessment of civil society participation is so important; one young person in Kenya said it best:

"The Declaration of Commitment is a tool for ensuring accountability. It sets an international standard toward which the government can work. It also gives individuals a mechanism for holding their government accountable. All UN members have signed the Declaration, therefore those who know its contents can use it to ask for action. This is why we (civil society) must be part of the process."

The diversity of factors affecting vulnerability, government structures, national incomes, health systems, amount of international financial support, number of donor and development agencies, and coordination mechanisms in the six countries studied shows that there can be no single approach to managing the UNGASS national review process. However, there were common themes that emerged from all of the case studies. It is assumed that these themes are also indicative of the processes in other countries managing the UNGASS national review.

The climate surveys conducted in Cambodia, Kenya, Malawi, Thailand, United Kingdom, and Vietnam all presented similar successes and challenges for ensuring the meaningful participation of civil society. While this report details several shortcomings in both government and civil society responses, many respondents were adamant that overall, collaboration between government and civil society was improving. Everyone interviewed was also eager to receive the capacity building necessary to improve the UNGASS national review process. Both government and civil society respondents stressed that if processes are not working, dialogue and support are needed. Several lessons learned and recommendations were made; here, they are grouped by theme:

⌘ **Weakened political commitment and leadership**

Many respondents felt that the first UNGASS national review process was managed better than this second round. The reasons cited were that there was a new and very vibrant global movement following the UNGASS meetings in June 2001. Government respondents especially felt that in 2005 there were too many competing priorities (e.g. PEPFAR, GFATM), and not enough resources placed behind managing, monitoring, and reporting on UNGASS. Oftentimes external consultants were hired to gather information and produce the national report for submission to the UNAIDS Secretariat in Geneva - instituting a minimal review process for civil society. In response, civil society gathered and submitted "shadow reports" as a separate process to ensure that their feedback was registered.

The assessment findings indicate the importance of strong political will and government leadership in the coordination of the UNGASS

¹⁵ This is also described in a letter from Dr. Peter Piot, Executive Director of UNAIDS, dated 11 August 2005, which summarizes the guidelines for country reports: "...The guidelines also emphasize steps to ensure a participatory and transparent approach throughout the report preparation process – from the planning phase to the submission of the final report to UNAIDS."

national review process. Without the anchor of government support, efforts to harmonize and align the data gathered were not effective.

Many respondents interviewed felt strongly that UNAIDS and other international partners played a catalytic role in linking civil society and government in the review process. The role of UNAIDS in organizing meetings, bringing in consultants and assigning writers to edit government UNGASS reports were critical steps for ensuring the report was compiled and submitted. However, this support did not always guarantee the meaningful involvement of civil society, a finding which is further outlined in each of the country case studies. Support from international partners also needs to be monitored carefully in order to strike a balance ensuring that external consultants are not driving a process that should be country-led. Feedback indicated that support from these partners must always be provided in a manner that ensures local ownership and strengthens government and civil society capacity to lead and participate.

⌘ **Inadequate systems and cumbersome structures** - Due to the large number and range of players in multi-sectoral AIDS responses, coordination within, as well as among, sectors and donor mechanisms remains a major challenge. This is especially true for decentralized governments, for whom gathering information and managing reviews require a high level of coordination. Some respondents to the assessment felt that the existing systems for managing and reporting on UNGASS were unwieldy, difficult to coordinate, and donor-driven. Those involved in the review process from civil society were often staff or leaders of NGOs or umbrella network organizations. This often led to the exclusion of smaller CBOs, NGOs, and FBOs who represented the most vulnerable groups in the community. Even though government and civil society organizations seemed to collaborate at the national level, this was not the case at district and rural levels. Respondents cited a need for mechanisms to effectively involve civil society in the UNGASS national review at these levels.

⌘ **Lack of clarity** - The importance of the UNGASS reporting process was not clear to many civil society (and some government) respondents. Some civil society groups did not understand why information was being collected when asked to provide data, or what was required of them when asked to comment. The relevance of

UNGASS was not clear to some groups, as the UNGASS indicators were considered very high-level and not reflective of grassroots activities.

⌘ **Inconsistent participation** - Civil society organizations interviewed were very enthusiastic about participating in the UNGASS process. However, they felt their participation could have been more meaningful had they been involved much earlier in the process. Only a few respondents interviewed were aware of a parallel process for civil society to submit information through shadow reporting. The larger organizations and networks were generally aware of these kinds of processes for civil society participation.

A lack of consistency with regard to the individuals participating in the process was also reported. For example, different individuals from civil society went to meetings during the review process and did not coordinate their information sharing in-house. Governments rarely, if ever, reported back to civil society on the final report after the data was gathered. This caused a lack of confidence from civil society in terms of whether the data they provided was used at all, whether it was used properly, and/or whether it was correctly interpreted. One major reason for this low rating could be that respondents were only involved in the final consultation meeting rather than during the whole process. Peri-urban and rural communities were almost never consulted or involved in the national review process.

The survey found that when governments involved civil society, PLHIV were almost always represented in the process, showing the importance placed on their involvement. The assessment findings also indicated that when there was participation from civil society, women were part of the process. However, in almost every case it was noted that most of the leadership and senior to middle management within PLHIV networks were men.

⌘ **Stigma as a barrier to civil society participation** - Stigma and discrimination remain a big challenge and limit the wider participation of the most vulnerable and marginalized groups in the UNGASS national reviews. Stigma and discrimination must be addressed, as they prevent PLHIV from being empowered and involved in the UNGASS national review responses. Initiatives aimed at reducing the prevailing climate of stigma and discrimination should focus more on the creation of nondiscriminatory

and supportive national policies. While this is an important component, policy alone cannot stem the tide of AIDS stigma and discrimination, much of which has been internalized by PLHIV. Ensuring greater public awareness of UNGASS and GIPA will help to address this issue.

⌘ **Varying capacities of monitoring and evaluation (M&E) systems and processes** - One of the largest obstacles for developing the UNGASS national reports was the lack of, or weakened, national monitoring and evaluation systems. This made it very challenging for governments to report the achievements against the UNGASS indicators. Instead, UNGASS reporting was most often managed as a project that came around every two years.

Most respondents said that they were more concerned about reporting on the indicators and targets agreed upon with their respective donor agencies. This meant that they monitored and reported progress toward donor agreements, which are not always aligned with the UNGASS indicators. For example, most organizations interviewed in Thailand said they were accustomed to the indicators and achievement targets negotiated with their donor agencies. This created a diverse and un-standardized set of indicators that were used by organizations throughout the country. Some of these indicators may be identical to those promoted by UNGASS, but many are likely to be different.

Kenya improved its M&E systems since the first UNGASS national review in 2003. The government developed one unifying M&E framework incorporating the UNGASS indicators.¹⁶ As well, Malawi has incorporated UNGASS reporting into its M&E framework.

Another obstacle was a lack of practical understanding and applicable knowledge of the DoC and indicators among government and civil society respondents. There was a concerted effort to strengthen civil society engagement in the national response in the context of the “Three Ones” principles (one national plan, one national coordinating body, and one national monitoring and evaluation system).

⌘ **Transparency and ownership** - While there were a number of participants involved in the

UNGASS reporting and review, in reality most processes were often driven by only a few people. The government office responsible for producing the UNGASS national review did not often share the report with other government offices and civil society organizations providing data. This prevented the opportunity for the participating agencies to review and provide recommendations regarding the entire report.

For example, in the United Kingdom elements of civil society were asked to draft a section of the country report and given a very short period of time to respond. There was a consultative process for the interim national report but little attempt was made to enable United Kingdom civil society to participate in a significant way, particularly PLHIV, vulnerable groups, and care-givers. No guidance was given on key questions or the basis for scoring performance, and no plans have been made to meet with civil society to review the outcome of the consultation.

More than half of the civil society organizations surveyed said they had little or no awareness that such a report was prepared or submitted. They also reported that they were not aware of the government agencies or individuals responsible for collecting the supporting data for the report. Further, results indicated that previous UNGASS reports submitted to UNAIDS were not shared with many of the key government or civil society agencies.

⌘ **Incomplete planning and poor capacity** - In every country surveyed, it was stated by both government and civil society respondents that the government authority mandated to lead the national UNGASS review process had limited capacity, staffing, and funding. These offices often lacked capacity for overall M&E coordination, information gathering, and analysis. Therefore, UNAIDS or other international partners most often funded the consultation process, and in many instances, wrote the UNGASS report. However, UNAIDS often provided financial support for national consultation workshops only. Almost no technical support was provided to civil society on how best to participate in the process.

Some civil society respondents also felt that they had limited capacity to fully engage in the nation-

¹⁶ NACC and NASCOP National Monitoring and Evaluation Framework for National Response to HIV/AIDS in Kenya (December 2004).

al review process. Thus for them to participate effectively, they needed more capacity building.

The fact that the UNGASS review process was often added onto other government meetings brought mixed reviews. Oftentimes the UNGASS national report and data collection was carried out in tandem with other information gathering. This had both positive and negative aspects; some respondents would have liked a process unique to UNGASS. The benefits of integrating the UNGASS process allowed for a more harmonized approach for linking reporting with the national program. Several interviewees implied that UNGASS and the review process might have been better understood if meetings had been dedicated specifically to the national report for UNGASS rather than added to other meeting agendas.

Time constraints also limited engagement. Many participants felt that the time frame for the national consultations held to prepare the UNGASS report and the writing process was rushed. This was also partly due to the late requests received by the governments from UNAIDS Geneva.

- ⌘ **Gaps in information sharing** – Most of the people involved in the assessment knew of the UNGASS for HIV/AIDS. There was, however, limited understanding of the Declaration of Commitment or how it specifically related to their countries and/or programs. This situation contributed to limited understanding of what the government was actually reporting on.

The official methods for information dissemination or data collection were often not clear to those who were interviewed. Many respondents mentioned information gathering, management, and dissemination challenges within the government – and within their own organizations and networks.

In cases where background information was adequate (e.g. UNAIDS or NAC briefings), the participants were not always able to access or understand the information. The lack of English skills (most meetings and documents were in English) was a recurring theme; it was difficult for many in civil society who did not have the necessary English skills to participate.

Modes of communication were often dependent on e-mail access, as most of the information concerning UNGASS was found on or disseminated by

the Internet. As most communication was written, anyone illiterate was left out of the process. Some respondents mentioned lack of contextual understanding when trying to reach audiences outside of the capital cities or in local languages.

The larger national networks did often assist with sharing and gathering information with their constituents and smaller CBOs and FBOs. In the future, resources should be dedicated to sharing information in an appropriate way, including the strengthening of civil society networks, so that more groups are involved in the process.

Do tools such as the *Greater Involvement of People Living with HIV/AIDS (GIPA) Principle* and the *Code of Good Practice for NGOs Responding to HIV/AIDS* help to guide partnerships between government and civil society?

Of the UNGASS Declaration of Commitment, GIPA Principle and the Code of Good Practice, GIPA was the best understood by most of the respondents from civil society, especially in the Asian countries surveyed. Many participants equated GIPA with non-discrimination or the visibility of people living with HIV. Several NGOs stated that GIPA meant the involvement of PLHIV in the design, implementation, monitoring, and evaluation of interventions.

Some persons misunderstood the GIPA principle to mean that persons identifying as HIV positive should work solely in the field of HIV and AIDS. In some cases, this was interpreted to mean that one should leave a trained profession to join a “separate” world of HIV and AIDS work, rather than seeing the interconnectedness of living positively and continuing in one’s own line of work. Others pointed out that being HIV positive did not make one an expert on HIV, nor did being positive endow one with more rights than anyone else.

The Code was established at an international level and has not been properly introduced at the country, local, or grassroots levels. The Code was virtually unknown to most organizations. Many people who had heard of the Code vaguely mentioned accountability and transparency standards when asked its contents and how it was used. One respondent pointed out that there was a high level of capacity needed to implement the Code, and that the ability to support this level of programming was not always available or well developed.

Building on existing efforts: Recommendations for improving civil society involvement

According to the intent of Article 94 in the DoC, members of civil society must be fully and transparently involved in the national consultation process. We have learned that reports and indicators developed without the input of civil society from the start are quickly criticized, and often are not reflective of what is really taking place in communities. Combining top-down and bottom-up approaches with governments and communities should be the basis for promoting strong partnerships. Information dissemination and dialogue help governments move beyond promoting the basic awareness of UNGASS toward ensuring civil society is involved at all stages of the national review.

- ⌘ **Provide support for capacity building and institutional strengthening for government and civil society** – Several interviewees stressed the need for building the capacity of government and civil society so the review process could be institutionalized, and not just managed by individuals. For example, in many cases, no operational plan with roles and responsibilities for collecting data for the UNGASS reporting processes exists. A mapping exercise or study on the current role and contribution of civil society should be conducted so that the government has a better understanding of how it may contribute to the national review process. The results should be widely disseminated so government and civil society understand their respective roles and importances within the AIDS response. The skills most often requested during the assessment by both government and civil society were:

Advocacy – The key to empowering civil society is to enable civil society to advocate on its own behalf. This includes a higher level of awareness of international agreements, such as the DoC. Civil society must be able to understand, apply, and demand accountability for international commitments. Advocacy on the part of civil society will help to educate all citizens on what their government has committed to, so that they can create demands for resources, encourage the government to remain committed, and introduce legal, policy, and programmatic reforms. Those interviewed felt that it is only when communities are informed that they will be able to hold their governments accountable. This is particularly important given the

high level of alleged corruption and poor accountability regarding the management of donor resources. The Global Fund grant in Kenya is an example whereof the audit report is long overdue. As one participant pointed out, advocacy does not lend itself to clear, tangible indicators, so it is often not prioritized in the results-based focus of the donor world. Advocacy must be prioritized if civil society is to become a true actor.

Monitoring and information collection – Government and civil society must do a better job of monitoring and documenting their work in order to be able to input effectively into processes such as UNGASS country-level reporting. The current emphasis is on implementation rather than analysis of impact. Civil society will be better able to negotiate with government if they have evidence-based information. Many noted that government should engage in more consistent monitoring. The new monitoring and evaluation framework should assign roles and responsibilities with regard to data collection. The success of government monitoring and reporting should in and of itself be monitored. Some suggested that the government offices responsible for the report disaggregate stakeholder contribution by sector, so as to clearly see the inputs of civil society, government, and private sector.

- ⌘ **Harmonize and strengthen national monitoring and evaluation systems** – The government must work with donors to create a harmonized approach to monitoring, evaluating, and reporting. Donors should provide support for M&E capacity building and participatory methods in order to strengthen reporting and partnership between government and civil society based on the “Three Ones” principles. It is important to ensure continuity for developing and strengthening systems to incorporate UNGASS review processes into ongoing government and civil society planning, implementation, monitoring, and reporting processes. The Declaration is often viewed as less important than the National HIV Strategic Plan’s (NSP) monitoring and evaluation plan. Standardized reporting formats compatible with national monitoring and evaluation systems should also be developed and used. Civil society, particularly people living with and affected by HIV and AIDS, must be involved in the development of indicators, collection systems, and information systems. They should not merely be called upon to “rubber stamp” reporting processes.

The overriding recommendation to ensure continuity is to develop and strengthen systems to incorporate review processes into ongoing government and civil society planning, implementation, monitoring, and reporting processes. Respondents pointed out that civil society lacks the capacity to institutionalize systems for information collection, dissemination, monitoring, and reporting on UNGASS and other international agreements. Their capacity must be increased in order to take on more challenges and strengthen systems.

The respondents also reported that different individuals from civil society went to meetings during the review process and did not coordinate their information sharing in-house. Thus various individuals within civil society had pieces of information on UNGASS that were never shared and put together. During a specific review process, inviting the same persons from involved departments would also help to ensure continuity. Alternatively, briefings must occur in-house and at meetings. Donors, NGOs and technical service agencies have a role to play in strengthening government and civil society capacity.

- ⌘ **Allow enough time for a transparent and participatory review** - All parties must have enough time to work together and to sufficiently consult before reaching consensus on what to include in the final report. More time should be allowed for adoption of the information and producing the final report – jointly owned by all stakeholders. More time ensures that civil society is represented in the process and their views are reflected. One principal recommendation was that the agency responsible for assembling the information for progress reporting to UNAIDS should convene a forum of the relevant HIV/AIDS agencies to: a) review the background of UNGASS and its importance to the national program; b) explain the progress reporting process – past, present, and future; and c) define the UNGASS indicators and targets. The organizers of the forum need to clearly articulate the objectives of the progress report, the process of assembling data for the response, and the time frame for completion. In addition, the responsible agency should extend the opportunity for civil society participation in all stages of planning, data collection, analysis, and the interpretation of findings.

- ⌘ **Define roles and responsibilities, and effectively manage expectations** - What is expected of each participant, including govern-

ment, civil society, public, national AIDS councils or authorities, etc? Who is responsible for information dissemination? What is the process for providing input and feedback? Where does one go to obtain more information? Assigning key point persons, even where there is no formal process, will allow access to those who want to participate. Developing clear roles and job descriptions, which include communications or information sharing, is critical. Assigning a specific person within the government to coordinate the UNGASS review is equally critical. Above all, there must be a clear understanding of government and civil society expectations of what the process can deliver.

- ⌘ **Ensure civil society participation and trust through participatory approaches** – Several respondents commented that the national review process has helped to bridge the gap in trust that is so commonly felt between the government and civil society. Promoting participatory approaches involving government and civil society can encourage ownership, sustainable partnerships and more effective responses. This is contrary to a more conventional approach, wherein governments, donor representatives and/or external consultants are primarily responsible for the process and response.

Developing systems of accountability to ensure the meaningful participation of PLHIV in the UNGASS review process was also one of the key findings. Therefore, applying the principles of GIPA (and perhaps the Code of Good Practice) to the management of the UNGASS review process will translate theory into action. Most respondents agreed that a combination of international and civil society advocacy ensured their participation in the UNGASS national review. That pressure needs to be maintained and backed with human and financial resources.

Ways and means of reaching peri-urban, rural-based civil society and groups representing the most vulnerable need to be explored. This calls for utilizing mediums other than written communications and the Internet. Strengthening national networks to improve their ability to reach out, disseminate to, and gather information from these communities can be one way to address this issue.

- ⌘ **Develop and implement effective communication strategies** – With support from donors and other local stakeholders, governments need

to arrange opportunities to explain the benefit of national UNGASS reporting processes to civil society. Raising awareness that the UNGASS indicators are part of a national framework would be beneficial, as most organizations were not aware they were reporting against these benchmarks. The responsible authorities should develop a communication strategy for disseminating all reports of national progress to wider audiences so that all AIDS stakeholders may fully understand the Declaration of Commitment on HIV/AIDS. Members of civil society should also integrate UNGASS as part of their communication and advocacy strategies to ensure that the issues are kept alive in their communities.

Conclusions

The climate surveys conducted in Cambodia, Kenya, Malawi, Thailand, United Kingdom, and Vietnam presented similar successes and challenges for ensuring the meaningful participation of civil society. This does not mean the issues presented in this report reflect all of the experiences in the countries managing the national UNGASS review process. However, the similarity of the experiences de-

scribed in the countries surveyed was striking. This indicates some level of validity with regard to the generalization of the overall management of the UNGASS national review process.

The task of identifying civil society's essential features and designing a strategy to involve all of the necessary stakeholders is, in itself, a complex but necessary process. Because the Declaration of Commitment for HIV/AIDS serves as an instrument for accountability at the national and international levels, integrating harmonized monitoring and evaluation systems, civil society partnership strategies, and effective advocacy and communication initiatives into the national HIV strategy will help to ensure a more active role for civil society in the future.

In order to secure the meaningful participation of civil society, especially PLHIV, rural populations and other vulnerable groups, governments must seek ways to share accountability and facilitate multi-sector inputs and consensus during the UNGASS national review. UNAIDS and other partners should also work closely with the government and civil society to ensure the systems are in place for managing an effective and participatory process at all levels in the government and community. ■

Section three

Country Profiles and Findings

CAMBODIA

Summary

In Cambodia the national response to HIV and AIDS continues to be vibrant. Government, civil society organizations, people living with HIV, and all development partners are actively participating in the response. Cambodia still has the highest HIV prevalence rate in the region with an adult (15-49) HIV prevalence rate of 2.6%, and an estimated 170,000 adults and children (0-49) living with HIV. There are an estimated 51,000 women (15-49) living with HIV, and AIDS deaths (adults and children) were estimated at 15,000 in 2003.

In Cambodia, prevention and care policies provide a sound basis for comprehensive, multi-sectoral AIDS responses. The government commitment to responding to the epidemic has been backed by enthusiastic donor support. Civil society organizations have taken on the main share of project implementation, with the private sector beginning to supplement efforts. With such a large number and range of players, coordination within, as well as among, sectors remains a major challenge. Several mechanisms address this challenge. The HIV/AIDS Coordinating Committee (HACC) brings non-governmental organizations (NGOs) working on HIV and AIDS together. The Cambodian People Living with HIV/AIDS Network (CPN+) is a support group composed of people living with HIV that has some 13 provincial-level chapters.

The UN Theme Group and Technical Working Group function effectively. The Country Coordinating Mechanism (CCM) for the Global Fund provides an additional forum for multi-sectoral participation. In addition, a sub-committee at the Global Fund oversees implementation and coordination in greater depth. A high-level multi-sectoral coordination committee has been formed, jointly chaired by the Chair of the National AIDS Authority and

the UN Theme Group Chair. This committee brings together donors, government, and civil society, and has seven Technical Working Groups, which are the basis of national planning and donor support.

While they report various challenges with regard to both government and civil society participation, many respondents were adamant that overall Cambodia is doing quite well. Evidence in support of this view includes:

- ⌘ the decline in the HIV prevalence rate;
- ⌘ the increasing number of people accessing VCT (170,000 in 2005), antiretroviral therapy (13,000) and treatment of opportunistic infections (20,000); and
- ⌘ the proper functioning of the HIV/AIDS Coordinating Committee - one of the few national coordinating bodies in the region.

In Cambodia, the UNGASS reporting process for many parts of civil society was in essence a non-event. Information and participation was largely confined to those who were involved in the Monitoring and Evaluation Advisory Group, and for those invited to the national consultation in December 2005. While the process is far from perfect, some lessons have been learned. According to most development partners, the government-managed UNGASS reporting process was effective.

The lack of a national monitoring and evaluation system is one of the country's critical challenges in terms of reporting achievements against the UNGASS indicators. Instead, UNGASS reporting is currently viewed as a project which comes around every two years. Many participants also felt that the time frame for the national consultation held on 9 December 2005 to prepare the UNGASS Report and the writing process was rushed. The National AIDS Authority (NAA) is mandated to lead the national UNGASS review process, however their ability to effectively undertake this role is limited due

to lack of capacity, staffing, and funding. Therefore, UNAIDS funded the consultation process and wrote the UNGASS report.

In terms of civil society involvement, the HIV/AIDS Coordinating Committee (HACC) coordinates and ensures information sharing. However, recently there has been a lack of capacity and staffing to support this function. A person has now been seconded to HACC for two years to help build capacity in communications and civil society coordination, which should hopefully improve the situation. Overall, the capacity of civil society to participate effectively in the UNGASS review and other national processes is poor. The lack of English skills (most meetings and documents are in English) creates difficulty for many in civil society. Information is not always translated into Khmer, which again hampers civil society participation in the national review processes.

After reviewing the findings from the assessment questionnaires, recommendations were provided for improving the participation in civil society in the UNGASS national review process. These included: suggestions for improving future UNGASS reporting; capacity building of government and civil society; emphasizing the meaningful participation of civil society (especially PLHIV); improving information sharing and communication; and integrating efforts (especially around M&E and reporting).

Sampling

For this report 21 people were interviewed, including fifteen men and four women from seven government departments or ministries, one United Nations functionary, one donor and 12 civil society members. A detailed list is provided in *Annex 2*.

Results

OVERVIEW OF THE PROCESS IN CAMBODIA

The model used in Cambodia for developing the UNGASS 2006 Report did not follow the processes described in the assessment questionnaire¹⁷. The process was compressed and somewhat rushed, which was reflected in the feedback from respondents.

UNAIDS Cambodia received the revised indicators¹⁸ from UNAIDS Headquarters Geneva in June 2005. The National AIDS Authority (NAA) Monitoring and Evaluation Advisory Group (including the NAA, NCHADS, Ministries of Education, Interior, and National Defense, DFID, USAID, CDC, UNAIDS, Khmer HIV/AIDS NGOs Alliance (KHANA), and FHI) held discussions and selected those indicators relevant to Cambodia, namely those dealing with a generalized epidemic and sex work. The most likely sources of data for the indicators were identified. Data was collected between June and December 2005 and several meetings of the Monitoring and Evaluation Advisory Group were held during this period.

Civil society was represented in the Advisory Group (e.g. KHANA, FHI and CPN+) and was consulted on the plan for data collection. Information was gathered either directly from civil society (KHANA), or indirectly from the government regulatory bodies that oversee certain organizations (e.g. NCHADS partners in the Continuum of Care – CoC). Technical support was provided to the NAA by UNAIDS, DFID, Family Health International (FHI), and a consultant was contracted by UNAIDS and Futures Group to assist the NAA.

A national consultation workshop on the preparation of the UNGASS Report was held on 9 December 2005 to assess data collected from the government, UN agencies and NGOs. Participants were invited through e-mail and through a formal letter dated 5 December. Respondents felt that this was appropriate, though many stated that the invitation was last minute. The HIV/AIDS Coordination Committee (HACC)¹⁹, KHANA and CPN+ participated in the workshop. Medicam, the national network of health sector-related NGOs, was not in attendance.

At the workshop, all existing data were reviewed and new information presented. An agenda was circulated, but according to interviewees involved in UNGASS for the first time, it did not provide enough background information. While this was a process led by the National AIDS Authority, the writing of Cambodia's UNGASS Report was undertaken by UNAIDS due to a lack of capacity in the NAA. Furthermore, UNAIDS provided financial support for the national consultation workshop. No technical or financial support was provided to civil society to participate in the process.

17 Please refer to Annex 1 for copies of the questionnaire.

18 UNAIDS (July 2005), Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators.

19 A network of some 90 NGOs.

Once the report was written, it was sent out to participants for comment. The time frame for comments was very short and some NGOs were uncertain as to what was expected of them. Input received was incorporated. It took three months for the NCHADS to complete the review, and for the Chairs of the NAA to approve the document before it was sent to the Ministry of Foreign Affairs for clearance. As such, the report was submitted to UNAIDS Headquarters after the deadline. To date, while some one hundred copies of the report have been recently produced, these have not been distributed to stakeholders and remain at the NAA offices.

The process was largely seen as consultative by those who participated. However, members of civil society who did not participate in the December meeting were completely unaware of the process. There are over 200 NGOs working on HIV in Cambodia. Those involved in care and treatment report to NCHADS. The HIV/AIDS Coordination Committee (HACC) only provided information on the UNGASS reporting process to a select number of member organizations. While NGOs may not have been aware of the process, they were represented by their umbrella organization and their data was taken into consideration. Grassroots NGOs stated that larger NGOs such as KHANA, and international NGOs such as CARE and FHI, need to participate more in visiting and monitoring activities at grassroots levels so information gathered nationally better reflects these realities.

While there were a number of participants involved in UNGASS reporting, in reality the process was driven by only a few people. However, the civil society organizations attending the consultation meeting agreed that there was no need for a Cambodian civil society shadow report, as the government and civil society agreed upon the data presented.

COLLABORATION BETWEEN GOVERNMENT AND CIVIL SOCIETY

National AIDS Authority (NAA)

The NAA is mandated to advocate, coordinate and undertake the monitoring and evaluation of the National Strategic Plan. The NAA reports directly to the Ministry Council, the Chair of which is the Prime Minister. The NAA has 26 member ministries and represents 24 provinces. Line Ministries and provinces are requested to provide quarterly reports to

the NAA. There are seven working groups responsible for operationalizing multi-sectoral responses. Some respondents to the assessment feel that the multi-sectoral response is unwieldy and difficult to coordinate.

The NAA should have most of the data on hand for the UNGASS reports through its Monitoring and Evaluation Unit. However, this is not the case because the NAA has only 1.5 staff working on monitoring and evaluation, and lacks capacity for overall M&E coordination, information gathering, and analysis. In terms of the UNGASS reporting process, several months were needed to collect data. There exists no operational plan with roles and responsibilities for collecting data for future UNGASS reporting processes. The NAA does not have a functional website for information dissemination. One respondent stated, "The NAA has great potential to fight HIV in a sustained way at the provincial level. However, capacity strengthening is needed in order to fulfill its mandate of providing leadership and coordination."

National Centre for HIV/AIDS, Dermatology and STDs (NCHADS)

The NCHADS, under the aegis of the Ministry of Health, has a reputation for working well in implementing care and treatment programs. Some gaps do exist; however, it does effectively monitor and evaluate its own work. According to NCHADS, a multi-sectoral response should involve strong partnerships with NGOs and all stakeholders for strategy and guidelines development, implementation, monitoring, and evaluation. The NCHADS sends operational workplans and quarterly reports to the NAA and to stakeholders. Reports are collected by partner NGOs and fed into NAA's data collection processes. Only now are links between NCHADS and UNAIDS being developed.

CIVIL SOCIETY STRUCTURES

Cambodian People Living with HIV/AIDS Network (CPN+)

The CPN+ was established in 2001 and has a Secretariat and secure funding; however, it is dominated by paid male employees. Most openly HIV-positive people attending meetings are women. CPN+ secured \$1.4 million through Round 4 of the Global Fund, which some respondents said is being spent on workshops and travel rather than benefiting grassroots PLHIV responses. CPN+ also received \$20,000 from KHANA.

Provincial networks have been established in 13 provinces, each maintained by two employees. CPN+ does not have a board providing strategic direction, review or ensuring transparency and accountability. The organization does have an Advisory Committee with terms of reference composed of five members (Director of NCHADS, one monk, and three PLHIV). Two national meetings have been held to-date, the last of which in 2002. There are no democratic organizational structures in place, which raises issues of accountability to members.

At the national level, CPN+ employs some high profile individuals but respondents felt they had limited capacity to work on the UNGASS national review process. Current staff members have university-level educations in fields such as veterinary science, architecture, and economics; however, they have had little formal training for their current roles. Nevertheless, CPN+ has given PLHIV issues visibility, and the organization works with other NGOs to ensure that they understand the need for involving PLHIV in their work.

Mondol Meth Chauy Meth (MMM's) – daycare centers attached to referral hospitals

28 MMM's and 15 referral hospitals have been established as an initiative of NCHADS. The majority of MMM members are women. The major benefit of the MMM structure is that it targets PLHIV locally, offering treatment for opportunistic infections. Participants receive money for travel (one of the principal barriers to access) and one meal.

HIV/AIDS Coordination Committee (HACC)

The HACC, initially established in 1992, is an NGO network with 90 member organizations and is one of the few coordinating bodies at the national level in the region. In terms of the UNGASS review process, HACC sent out information and the report for comment to only a select number of member organizations rather than to its full constituency²⁰.

The HACC has low capacity for coordination; however, a consultant was recently seconded for two years to assist in this effort. Inter-governmental coordination is another issue since the NAA was established to coordinate the national response. It was expected that the HACC and others would access financial support for coordination through the NAA rather than being directly funded for such work by donors. Other NGOs flagged the

need for capacity building. HACC has a website, though it is light in content. The HACC noted that many of its members have technology limitations; downloading large files can strain e-mail capacity. Further, large documents in English tend to be ignored or not read, as English skills are often limited.

Other issues

GIPA PRINCIPLE

Knowledge of the GIPA Principle in-country is somewhat confused. There is an UN GIPA program in Cambodia, which has meant that many of the interviewees equate the GIPA program with the Principle. Many participants linked GIPA with non-discrimination or visibility of people living with HIV. Several NGOs stated that GIPA meant the involvement of PLHIV in the design, implementation, and monitoring and evaluation of interventions. The NCHADS talks about RIPA – the real involvement of PLHIV – through creating an enabling environment for PLHIV using the MMMs. The MMMs are designed as a forum where PLHIV can support one other.

THE CODE OF GOOD PRACTICE FOR NGOS

Of the UNGASS Declaration of Commitment, GIPA Principle and the Code of Good Practice, GIPA is the best understood in Cambodia. The Declaration of Commitment is only used or understood by those directly reporting on or working with it at a national level. One respondent noted that while the DoC and GIPA are useful, in the case of Cambodia these concepts have been implemented nationally over the last 10 years. The international emphasis on these issues is somewhat late in coming. The Code of Good Practice has had little impact on the NGO sector. However, it was distributed to interviewees as part of the assessment process.

LINKS TO OTHER PROCESSES AND DOCUMENTS

The UNGASS Declaration of Commitment is viewed as less important than the National Strategic Plan's (NSP) monitoring and evaluation plan. There is a need for harmonization by developing an action plan to operationalize the NSP under the auspices of the NAA. Many interviewees noted that the NAA has yet to establish a national monitoring and evaluation system – something that has been promised for years.

²⁰ HACC held a workshop on making UNGASS work in Cambodia in December 2003. The participants from this workshop were the ones that HACC has continued to involve in subsequent UNGASS discussions.

SHADOW REPORT

With the exceptions of HACC and CPN+, NGOs interviewed were unaware that UNAIDS has a parallel process for civil society to submit information directly to UNAIDS headquarters for UNGASS reporting. This reflects the general lack of knowledge and participation of interviewees around the UNGASS reporting process.

LANGUAGE CONSTRAINTS

There is a problem of terminology, as many words may not exist in Khmer or their meaning may be slightly different. Many people have limited English skills, and basic materials are not translated into Khmer, creating additional barriers to involvement and effective participation.

Conclusions and recommendations

While some of the recommendations are specific to the UNGASS reporting process, most interviewees made recommendations concerning relations between stakeholders. Both government and NGO respondents stressed that if processes are not working, dialogue is needed.

- ⌘ **Future UNGASS reporting** – The NAA needs to improve its coordination role, especially with regard to information dissemination. This can be achieved if technical assistance is provided to the NAA to establish a functioning website in English and Khmer with all documentation on the Cambodian HIV response. The NAA should arrange opportunities to explain the benefit of national UNGASS reporting processes to civil society, particularly local level NGOs, as the obligations under UNGASS are not clear to them. It is also important to institute a two-year planning process led by the NAA with UN and NGO partners. Dates and clear roles and responsibilities should be listed for each stakeholder, including PLHIV organizations and vulnerable populations. Standardized reporting formats compatible with the national monitoring and evaluation system should also be developed and employed.
- ⌘ **Capacity building** – Donors need to work with the NAA and the Deputy Chair to ensure that the monitoring and evaluation unit is staffed with people skilled in M&E, report writing and communications. UNAIDS can help to convene a meeting between HACC and NAA to develop a joint proposal for donor support to develop HACC's capacity to coordinate civil society. They can also second qualified staff to CPN+ for a minimum of two years for capacity building, including computer skills, knowledge management, strategic planning, developing operation plans, reporting, training of staff, information sharing, etc. This will help to strengthen the involvement of PLHIV networks so they can more effectively partner with the government.
- ⌘ **Meaningful participation** – It is important to increase civil society participation in processes, including, but not limited to, UNGASS reporting. This can be achieved through the Monitoring and Evaluation Working Group or by inviting NGO representatives to initial discussions about indicators. With the support of UNAIDS and other stakeholders, the government could hold meetings prior to national consultations to provide civil society with the necessary background information. Depending on the capacity of the participants, such a pre-meeting could be used to formulate and facilitate civil society's development of inputs to the data collection process. Civil society should also be invited to technical working group meetings with terms of reference developed to clarify roles and responsibilities. These groups could report to the NAA using standardized formats developed by the Monitoring and Evaluation Advisory Group.
- ⌘ **Information sharing and communication** Improve flows of information from networks (CPN+, HACC, MEDCAM, EDUCAM, and Cambodian Committee for Coordination) to NGO constituencies. HACC and CPN+ capacity building should be a priority. UNAIDS could help facilitate a dialogue with large NGOs to broaden the support base for CPN+ and HACC.
- ⌘ **Integrated efforts** – Some government ministries and NGOs are working with the same vulnerable populations (i.e. sex workers), but separately, causing a potential duplication of effort. UNAIDS, other UN agencies, and donors should work with the government to help develop standardized methodologies and integrated program design in order to prevent duplication. Vulnerable populations should also be invited to participate in this process so that their voices and opinions are heard and reflected. ■

KENYA

Summary

Kenya has made great progress in its fight against HIV and AIDS in the last decade. Since the inception of the Declaration of Commitment, Kenya successfully implemented its national HIV and AIDS strategic plan and witnessed a decline in HIV prevalence from 10% in the 1990s to 7% in 2003.²¹ More recent sentinel surveillance data indicates that adult prevalence has fallen even further, to 6.1% by the end of 2004.²² Evidence suggests that this dramatic turnaround is the result of a combination of factors, which include higher death rates, lower incidence, and behavior change. In the case of Kenya, evidence suggests that significant numbers of Kenyans have adopted safer sexual behaviors in recent years, including increased condom use, delay in first sexual experience and reduction of partners.²³

Kenya has also developed one unifying M&E framework.²⁴ The completed strategic plan of 2005 has been evaluated and the findings have informed the 2005-6 to 2009-10 strategic plan. In Kenya's new strategic HIV plan, vulnerable and marginalized groups; including the disabled, OVC and commercial sex workers feature more prominently as target groups to be addressed than in the completed strategic plan.²⁵

The National AIDS Control Council (NACC) is responsible for collecting data on the UNGASS indicators, producing the UNGASS report, and ensuring stakeholder involvement. The sub-committee on Monitoring and Evaluation was tasked with overseeing the process to provide technical feedback. At the national level, the NACC was also responsible for carrying out the annual Joint AIDS Program Review (JAPR), which is the mechanism for enhancing a multi-sectoral approach to fight HIV and AIDS, and strengthening coordination among all stakeholders. It provides a forum in which the National AIDS Control Council, the Ministry of Health, the government of Kenya, civil society, the private sector, and development partners come together annually, building on quarterly sector meetings.

Since 2002, the NACC has convened an annual forum for all stakeholders to review the progress made in the delivery of the Kenya National HIV/AIDS Strategic Plan (KNASP). This Forum has proved a useful mechanism for monitoring the Kenyan AIDS response, and is used to highlight particular critical issues and monitor progress. This year, the critical issues included: a) attention to the mainstreaming of AIDS into the national planning process and budget cycle, and b) the strengthening of civil society engagement in the national response in the context of the "Three Ones" principles.

During the 2005 national review, the government was receptive to civil society participation and engaged with them on a limited scale. The 2005 Kenya country report submitted to UNAIDS included prominently displayed contributions from civil society. This was a departure from 2003, when Kenyan civil society was not part of the formal review and reporting process. They engaged in shadow reporting only.²⁶ In 2005, Kenyan civil society leaders chose to input their views and feedback into the official government report. All interviewed in this study agreed that progress has indeed been made.

Civil society organizations interviewed during the assessment were very enthusiastic about participating in the UNGASS process. However, they felt their participation could have been more meaningful had they been involved much earlier in the process, and been allotted more time. They also expressed the need for more information about UNGASS, as the general lack of knowledge concerning the Declaration of Commitment and the national review process compromised civil society input in the Kenya report. Some civil society respondents also felt that they have limited capacity to fully engage in the UNGASS and national review processes. Thus, capacity building is the key to their effective participation.

The general mood in Kenya around the UNGASS review remains positive and optimistic. Most participants welcomed the opportunity to provide input. They recognized their own limitations but saw the process as a learning opportunity, and were highly engaged in finding ways to improve future reporting. Several respondents commented that this process of national review has helped to bridge the

21 AIDS Epidemic Update:J 2005, UNAIDS and WHO, p. 27.

22 Kenya HIV and AIDS Data Booklet, NACC 2005.

23 AIDS Epidemic Update, UNAIDS/WHO 2005.

24 NACC and NASCOP National Monitoring and Evaluation Framework for National Response to HIV/AIDS in Kenya (December 2004).

25 Kenya National HIV/AIDS Strategic Plan (KNASP) 2005/06-2009/10.

26 This was done through the International Council of AIDS Service Organizations (ICASO)'s "In-Country Monitoring of the Implementation of the Declaration of Commitment Adopted at the UNGASS on HIV/AIDS: A Four Country Pilot Study." June 2004.

gap in trust that is so commonly felt between the government and civil society.

Sampling

In carrying out the climate survey, the UNAIDS list of who was involved in the UNGASS national review was reviewed in order to select the respondent sampling. The majority of the participants (more than 80%) of the UNGASS civil society working group were interviewed and completed the questionnaire. Recognizing the time constraints of the review process, networks were the ideal target to ensure civil society participation – therefore, the larger networks in Kenya were interviewed. Interestingly, the majority of those interviewed were women. FBOs were also represented amongst the interviews, including Catholic and Muslim representatives.

The assessment coincided with an East Africa regional meeting of religious leaders living with or personally affected by HIV and AIDS in Nairobi, organized by KENERELA and CARE International. This made it possible for some marginalized groups, such as Muslim women in rural areas, to be interviewed. Persons openly living with HIV made up at least 17% of the respondents. Most interviewees were not familiar with UNGASS and the DoC. When the civil society participants were asked how they felt about the UNGASS national review process, they were generally pleased to have been included and positive about the fact that government and civil society did present a joint report. Below are some of the main comments on the process.

Results

OVERVIEW OF THE PROCESS IN KENYA

Civil society in Kenya was proactive in participating in the 2005 national report. UNAIDS played a major role in engaging civil society in the national review process. A meeting with several civil society leaders was held on 18 November 2005 to discuss the country report for UNGASS review. After hearing an overview, and noting the willingness of the government to include civil society in the process, the group decided not to produce a shadow report. With the help of UNAIDS, they formed a civil society working group to plan and coordinate input into the national report.²⁷ During this meeting membership in the working group was discussed

to make sure that the appropriate staff was represented – the person who was able to represent the interests of their constituents. Members were identified from major NGO umbrellas, PLHIV networks, youth, faith-based organizations, and vulnerable groups such as women.

The NACC has recognized the importance of involving civil society by including it in the JAPR, and other structures and processes. For example, the NACC undertook a consultation with civil society to help determine the priorities of the new Kenya National HIV/AIDS Strategic Plan. In preparation for the UNGASS national review meeting this year, the NACC conducted a series of consultative meetings with civil society in November 2005. These meetings focused on youth, PLHIV, persons with disabilities, faith-based organizations, the private sector, and non-governmental (NGOs) and community-based organizations (CBOs). One meeting focused on vulnerable groups and invited representatives of pastoralists, commercial sex workers, drug users, refugees, and men having sex with men (MSM). These meetings were designed to include a briefing on the Declaration of Commitment.

With the help of UNAIDS, a civil society working group was established to work with the Monitoring and Evaluation sub-committee of the NACC to capture civil society information and input. According to the terms of reference agreed upon by the members, this working group was to participate in M&E sub-committee meetings.²⁸ The M&E unit at the NACC was placed in charge of developing the report, providing an avenue for civil society participation. This group has two objectives:

- ⌘ to assist the NACC M&E unit in formulating the Kenya UNGASS report for 2005;
- ⌘ to assure civil society participation in the General Assembly special meeting in 2006.

The civil society working group held another meeting to address issues to be included in the UNGASS report on 2 December 2005. Civil society comments were included in the draft of the report and the draft was circulated to all members for comments. Finally, a meeting was held on 16 December 2005 with all stakeholders to review the national report to be submitted to UNAIDS. Civil society organizations were invited to the meeting and the working group was asked to provide a re-

²⁷ Minutes of the UNGASS reporting/CSO working group meeting held on 18 November 2005 are at KANCO Resource Centre.

²⁸ As stated in the Terms of Reference for the working group.

view of the draft report. Civil society commentary in the report was highlighted within the narrative as separate text.

"This was a learning process."

For the first time the government invited civil society to contribute to the review process by submitting a joint report. Networks of PLHIV were given opportunities to serve on the civil society working group to increase their participation in planning. Government and civil society groups listened to each other's concerns, and worked together to address them in the draft. Opportunities for civil society to contribute were made available by inviting staff from these organizations to participate. There was a concerted effort to represent different groups by working through networks.

Most of the people involved in the assessment knew of the UN General Assembly Special Session on HIV and AIDS (as well as the Special Session on children the following year). There was, however, limited understanding of the Declaration of Commitment or how it specifically related to Kenya. This situation contributed to a limited understanding of what the government is actually reporting on. The UNGASS indicators or how they fit into the framework of the UNGASS DoC are not well understood. Some respondents knew about UNGASS from the 2001 meeting; while others learned about it through the national review process.

⌘ **The process was driven by motivated individuals.** In this case, the dedication of the individuals who served on the civil society working group, and their personal commitment, drove the involvement of civil society. Unfortunately, the capacities of some of the institutions involved were cited again and again as being weak. Several interviewees stressed the need to build the capacity of civil society and strengthen systems so the review process could be institutionalized, and not just managed by individuals.

⌘ **UNAIDS provided support for the process.** Many respondents interviewed strongly felt that UNAIDS played a catalytic role in linking civil society and the government in the review process. The role of UNAIDS in its ability to organize meetings, bring in consultants and assign an editor to the government UNGASS report, were critical support for ensuring the involvement of civil society.

COLLABORATION BETWEEN GOVERNMENT AND CIVIL SOCIETY

"Participation is only as strong as the individuals inputting information."

"There was not enough time to learn about the Declaration and provide informed input."

Those involved in the review process from civil society were staff or leaders of NGOs or umbrella network organizations. Civil society participants were based in Nairobi, and were not supported (in terms of resources and capacity) to reach their members countrywide. There was broad agreement that this national review did not reach the grassroots level. Persons outside of large civil society organizations in Nairobi were also left out of the process. Individual participation in larger national networks did not ensure representation as there was limited mobilization of constituencies during the brief national review process. Some respondents commented that private and public sector participation should have been greater. Several persons mentioned the vulnerability of the girl-child and the need to focus more attention on her representation.

The overall rating about the process fell evenly between "functional" and "consultative", with two votes for "passive" and one for "interactive". The vast majority of respondents felt that the government consulted them, but after the development of the indicators and data collection were already completed. Civil society was not sufficiently involved in determining indicators, developing a process for information gathering, or inputting data directly into the formal process. Many respondents felt they were merely being asked to "rubber stamp" an existing report. Some mentioned their involvement was "token" rather than meaningful.

Table 1 Kenya – Civil society agency perception of level of participation in preparing the progress report on UNGASS indicators

Perceived level of involvement	Number of respondents
Interactive involvement	1
Functional involvement	5
Consultative involvement	5
Passive involvement	2
Total	13 out of 22 interviewed

⌘ **The lack of applicable knowledge of the Declaration of Commitment limited the process** – Both in the government and among civil society, there was a gap in a practical understanding of the application of the Declaration of Commitment.

⌘ **The fact that the UNGASS review process was added onto other NACC meetings brought mixed reviews** – The fact that the UNGASS national report and data collection was carried out in tandem with the JAPR had both positive and negative aspects. Some respondents would have liked a process unique to UNGASS. Several interviewees implied that UNGASS and the review process might have been better understood if meetings had been dedicated specifically to the national report for UNGASS rather than added to other NACC meeting agendas such as JAPR.

Others found the idea of tying UNGASS review meetings to JAPR meetings a logical combination. However, they pointed out that UNGASS and its links to the national strategic plan, and monitoring and evaluation framework should have formed a separate agenda. A clearer explanation of the agenda item, even within the meetings, was requested by everyone. Respondents had a difficult time figuring out which process they were involved in and how that related to UNGASS. Without prior sensitization and background information, participants sometimes felt unable to contribute effectively. This comment came from government, the National AIDS Control Council and civil society respondents.

⌘ **Time constraints limited engagement** – The process for completing the national review did not start until November 2005. This was not an adequate amount of time to meaningfully engage all participants. As mentioned above, UNGASS was added on to other meetings, but even then, UNGASS itself was not allotted much time. Members of civil society and government have overloaded schedules, and some who received the draft report did not have the time to devote to a proper review.

⌘ **Civil society commentary was reflected** – One of the questions asked of participants was whether or not their input was adequately and appropriately reflected. At the time of the in-

terviews, only the draft version of the report had been circulated. Despite its dissemination by UNAIDS, many interviewees had not yet read the document. From the limited response of those who did, it seems that the boxed commentary from civil society was accurate and reflected the discussion that had taken place.

Other issues

GIPA PRINCIPLE

In discussions around GIPA, the majority of interviewees were familiar with the Principle of Greater Involvement of Persons Living with HIV and AIDS. Some focused on the greater involvement of only positive persons, while others interpreted the GIPA principle as meaning greater involvement of those infected and affected by HIV.

Some persons misunderstood the GIPA Principle to mean that persons identified as HIV positive should work solely in the field of HIV and AIDS. In some cases, this was interpreted to mean that one should leave a trained profession to join a “separate” world of HIV and AIDS work, rather than seeing the interconnectedness of living positively and continuing in one’s own line of work. Others pointed out that being HIV positive does not make one an expert on HIV, nor does being positive denote one with more rights than anyone else.

In several cases, resources were brought into the discussion around GIPA. Several participants commented on the lack of government resources dedicated to PLHIV. Others implied that resources to advance GIPA should go only to HIV positive persons – that somehow being positive implies ownership of the funding.

THE CODE OF GOOD PRACTICE FOR NGOS

The Code of Good Practice for NGOs Responding to HIV and AIDS sets out guiding principles which apply a human rights approach to a range of HIV and AIDS-specific health, development, and humanitarian work undertaken by NGOs responding to HIV and AIDS.²⁹ The Code was established at an international level and has not been properly introduced at the local or grassroots level. The Code was virtually unknown to most organizations interviewed in Kenya. Many people who had heard of the Code vaguely mentioned accountability and transparency standards when asked its contents and how it was used.

29 The Code of Good Practice for NGOs Responding to HIV and AIDS, page 10.

The Kenya AIDS NGO Consortium (KANCO) is a signatory to the Code. KANCO and others who are familiar with the Code recognized that it set out strong standards toward which national level NGOs should be striving. One respondent pointed out the high level of programming needed to implement the Code, and that the capacity to support this level of programming is not always available or developed. The Code, as noted by another respondent, does not allow for cultural or religious biases, leading to the segregation of marginalized groups such as men who have sex with men, sex workers, or PLHIV in Kenya.

LINKS TO OTHER PROCESSES AND DOCUMENTS

"Processes like these should be facilitated with one place to go for information."

The official method for information dissemination and collection around the national UNGASS review is not clear to many who were interviewed. Many respondents mentioned information gathering, management and dissemination challenges within the government, as well as within their own organizations and networks.

In cases where background information was adequate (i.e. UNAIDS briefings), the audience was not always able to access or understand the information. Modes of communication are dependent on e-mail access, as most of the information concerning UNGASS is found on or disseminated by the Internet. Because most communication was written, anyone illiterate was left out of the process. Some respondents mentioned lack of contextual understanding when trying to reach audiences outside of Nairobi or in local languages.

Conclusions and recommendations

The government and civil society have demonstrated the will to engage in strengthening their cooperation in monitoring international commitments. Some interviewees remarked that they "appreciate that we have come a long way and a lot of good work has been done." This process helped to remove some of the past skepticism between government and civil society. Because of the avid interest in improving the process of engagement, many recommendations were made, and are grouped below by theme:

⌘ **Expand the reach of the process beyond Nairobi to rural parts of Kenya** – Ways and means of reaching rural-based civil society need

to be explored, and this calls for utilizing mediums other than written communications. Strengthening networks by building capacity to improve their ability to disseminate information to the members of their own communities can be one way to address this issue. Plans to more effectively engage with the Constituency AIDS Control Committees (CACCs) within the NACC, and the NACC regional offices in the dissemination of information will also help to expand participation.

⌘ **Donors need to continue to support and encourage civil society participation** – Most respondents agreed that a combination of international and civil society advocacy ensured their participation in the UNGASS national review. That pressure needs to be maintained and backed with resources.

⌘ **Allow enough time for a transparent and participatory review** – All parties need to have enough time to work together and to sufficiently consult before reaching consensus on what to include in the final report. More time should be allowed for adoption of the information, and producing the final report – jointly owned by all stakeholders.

⌘ **Define roles and responsibilities, and effectively manage expectations** – What is expected of each participant, including government, civil society, public, NACC, etc.? Who is responsible for information dissemination? What is the process for providing input and feedback? Where does one go to obtain more information? Assigning key point persons, even where there is no formal process, will allow access to those who want to participate. Developing clear roles and job descriptions, which include communications or information sharing, is critical. A specific person within NACC should be assigned to coordinate the UNGASS review. Above all, have a clear vision for government and civil society expectations.

⌘ **Dedicate resources for capacity building** Financial support and technical assistance were the most common requests during the assessment, especially for advocacy, monitoring and evaluation. Respondents pointed out that civil society currently lacks the capacity to institutionalize systems for information collection, monitoring, and reporting on UNGASS and other international agreements. Their capacity must be increased in order to take on more challenges and strengthen systems.

⌘ **Ensure continuity by developing systems**

The majority of respondents requested a continuous process for information collection. Various suggestions included organizing a standing committee dedicated to the DoC to ensure that there is a continuous monitoring and reporting body specific to UNGASS. This should include an all-inclusive standing body composed of civil society, the government, and UNAIDS. Respondents also reported that different individuals from civil society went to meetings during the review process and did not coordinate their information sharing in-house. Thus, various individuals within civil society had pieces of information on UNGASS that were never shared

and put together. During a specific review process, inviting the same persons from involved departments will also help to ensure continuity.

⌘ **Involve civil society throughout the process**

Civil society and the public sector should work together from the beginning. Members of civil society would like to be involved in determining indicators by designing the monitoring and reporting processes with the government. This should be an ongoing process as it is updated and repeated, so there is an opportunity for key players to work together to ensure continuous participation, and avoid the “rubber stamping” of final reports.

Discussions with civil society seem very far removed from the reality of the people who, for example, live in Kibera, Kenya’s largest slum. Are review processes like UNGASS, carried out for the UN Special Session, relevant for someone who is struggling to find his or her next meal? Should we be spending time and money to strengthen reviews such as these? While in Kibera, in meetings with civil society and government, these questions were raised. The answer, surprisingly, was a resounding yes.

When asked why, respondents in government and in civil society mentioned that international agreements and standards give the country a goal to strive toward. They explained that the pressure must come from the international com-

munity in order for the government to respond. Accountability and transparency were mentioned. One youth group member stressed that international meetings must take place for the following reasons: *“The Declaration of Commitment is a tool for ensuring accountability. It sets an international standard toward which the government can work. It also gives individuals a mechanism for holding their government accountable. All UN members have signed the Declaration, therefore those who know its contents can use it to ask for action.”*

In Kenya, unfortunately, there are few who understand its applicability. In order for the Declaration to realize its potential, more parts of civil society must be able to demand its implementation.

Toward a Meaningful Involvement of Sex Workers in Kenya

Prof. Elizabeth Ngugi is an outspoken voice for the rights of women and sex workers, and has worked for over twenty years in these fields. A renowned professor in Health Sciences at Kenyatta University in Nairobi, she began her studies in HIV and AIDS in 1985 while she was a student at the university. As part of her research, she traveled to Majengo, in Kenya's Western Province, to study and research the sexual practices of what was then Kenya's most well known prostitution district. Her initial research led her to discover that prostitution was rampant in the area because the sex workers, mainly women, had no other means by which to support their families. Many of the women were having sex with 2-5 different partners a day in order to earn enough money to feed and support their families. Most of the women were having unprotected sex and were suffering from various sexually transmitted infections (STIs), and did not know their HIV status. During their encounters with men, they were often the victims of physical and mental abuse.

Further research in Nairobi led Prof. Ngugi to discover that the rights of sex workers are abused and neglected not only by their clients and local communities, but also by the official authorities. "Sex workers who sought medical consultation at that time were often hampered on purpose by the persons in the clinics they visited," she said. She recounts stories wherein sex workers would visit a clinic in search of medical aid but were told it was not possible for them to see a doctor or receive treatment without the presence of their partner. "These women were having up to five partners a day," she says, "which of their partners were they expected to bring?" The women would leave the clinic, go out to the street and pay someone a small bribe to pretend that they were their partner, return to the clinic and receive the necessary treatment.

Currently, Prof. Ngugi is the director of the Kenya Voluntary Rehabilitation Center (K-VOWRC), a project which she started soon after her research at Kenyatta University. Initially, K-VOWRC began as an organization that set up clinics for sex workers because of their lack of access to suitable medical facilities due to discrimination. The centers also educated sex workers about safer sex practices and their rights. More recently, the orga-

nization has widened its scope to include women, especially those in rural areas, because of the lack of education they receive due to the conservative nature of traditional Kenyan culture. "Women in Africa are disadvantaged, there are huge inequalities. They are disempowered socially, politically, and economically, and this is why they are the most infected," she says. "Many cultures still regard a women's correct place as being at home. Women are expected to tend to domestic chores while men are considered the bread earners."

At present prostitution is an illegal practice in Kenya. Prof. Ngugi estimates that over 80% of sex workers do not use a condom because they are discriminated against – and they are not in a position to negotiate. As a result, between 40-60% are infected with STDs, including HIV and AIDS. She discovered that the most prominent areas for sex workers to operate are along Kenya's main road trading and transport routes. "Prostitution is not going to go away, so it is necessary to include them (sex workers) in our future planning because their clients come from all walks of life," she says.

Her projects have had such success that the Kenyan government invited her to participate in their review of the United Nations General Assembly Special Session (UNGASS) on HIV and AIDS. The government has also begun to support her organization and asked her for her input as to how to respond to sex work. On Prof. Ngugi's recommendation, government experts also met with a group of sex workers to get their feedback on how to deal with the epidemic in Kenya.

Prof. Ngugi believes that with the support of the government, Kenya is now moving in the right direction to effectively fighting HIV. She identifies poverty, human rights, legal rights, stigma and prejudice, poor HIV education curricula, and the lack of government manpower and medical infrastructure as the largest obstacles to dealing with the problem. "The solution," she says, "is simple. It is meaningful participation and meaningful involvement." She believes that the best way to address the issues is at the grass roots level and to involve all areas of society to contribute to ensure that the responsibility does not fall on any one group or organization, "that way, everyone is responsible." ■

MALAWI

Summary

Malawi has one of the highest HIV infection rates in the Sub-Saharan Africa region. HIV/AIDS is now the leading cause of death in the most productive age group of 15-49 years old, with conservative estimates putting the HIV infection rate at around 15% nationally.³⁰ HIV/AIDS accounts for over 70% of all in-patient admissions in Malawi. The National AIDS Commission estimates that the infection rate in women attending ante-natal clinics varies from 10% in rural areas to 30% in urban areas (Ministry of Health). As a result, AIDS threatens the social and economic well being of Malawi and other countries in the region.

All sectors of Malawian society have been affected by HIV. Leaders, including the current president, Dr. Bingu Wa Munthalika, and the former vice-president, Dr. Justin Malewezi (M.P), have taken an active role in talking openly about HIV and AIDS. However, many Malawians are still silent about how the disease affects them on a personal level. Stigma, discrimination, and lack of access to appropriate services are among some of the challenges to effectively addressing HIV and AIDS. Few Malawians know their status; some are afraid to seek out this information due to stigma, while those who do want to know their status lack access to testing services.

There are no laws that specifically protect PLHIV and other vulnerable groups from discrimination in Malawi. However, provisions from the constitution and from certain laws³¹ address the issue of equality and non-discrimination. "There is a general feeling that [this] is insufficient, and that legislation needs to be adapted to deal with the HIV/AIDS situation."³²

Women and girls in Malawi are disadvantaged socially and economically. Within the education system, more boys than girls attend primary school despite access to free education at that level. The gap widens significantly at the secondary and tertiary levels. "In 2002, the literacy rates among people aged 15 and above were 79% for males and 46% for females."³³ The literacy rates were worse in rural than in urban areas – 77% vs. 99% for males,

and 42% vs. 72% for females."³⁴ Women and girls are at high risk of victimization and HIV/STI infection. As in many other African countries, they also bear a disproportionately heavy burden for providing care to family members and others.

Sampling

Interviews were conducted with three government departments and committees, two national PLHIV organizations, one national AIDS service organization, one national civil society organization, and four CBOs who operate in the rural areas of Lilongwe district. The assessment findings are the reflections of these organizations, yet most of the responses were consistent, indicating that it may be possible to generalize the issues for Malawi.

Since the UNGASS indicators were integrated into Malawi's National HIV and AIDS M&E Framework, the questionnaire was modified to gauge the level of civil society participation in the collection of data and review of national reports.

Results

OVERVIEW OF THE PROCESS IN MALAWI

In 2001, the government of Malawi (GOM), demonstrating its commitment to mitigating the epidemic across all sectors, transferred the responsibility of coordinating the national response to HIV/AIDS from the Ministry of Health (MOH) to the Office of the President and Cabinet (OPC). At this time, the old National AIDS Control Programme (NACP), which was established in 1989 and housed at the MOH, was replaced with the National AIDS Commission (NAC). The NAC is composed of a Board of Commissioners and a Secretariat (NAS). The Board's 19 commissioners are drawn from civil society, the public and the private sectors, and a representative of people living with HIV/AIDS.

In 1999, Malawi developed the National HIV/AIDS Strategic Framework (NSF) and in 2003 the National HIV/AIDS Policy was approved by the GOM. "According to civil society organizations such as the National Association of People with HIV/AIDS in Malawi (NAPHAM) and the Malawi Network of People Living with HIV/AIDS (MANET+), the pro-

30 UNAIDS.

31 The Malawi Constitution of 1994 and Employment Act of 2000 address discrimination and can be applied to protect PLHIV in the workplace and health settings.

32 Quoted from UNGASS Monitoring Civil Society Perspectives, Malawi, Panos Southern Africa.

33 DHS EdData Survey, 2002.

34 Quoted from Malawi HIV and AIDS Monitoring Report 2005, pg. 6.

cess for developing the national HIV/AIDS policy was very consultative."³⁵

The National AIDS Monitoring and Evaluation (NAME) System was developed in 2004 to track national progress in achieving the objectives of the NSF. The national M&E framework for Malawi incorporates the UNGASS indicators. The NAC collects data from any organization that carried out HIV or AIDS programming, irrespective if the funding came from NAC or another donor. This information was collected through the NAC Activity Report System (NACARS). It is a national requirement for all projects that are implementing HIV or AIDS activities to report to the National AIDS Commission through filling out and submitting the NAC activity reporting form. However, organizations that have not received funds from NAC are not enthusiastic about fulfilling this requirement; experience has shown that those who have received funds from the NAC are more willing to do so.

Since 1999, the GOM has been engaged in a decentralization process of all government services and gradually transferring authority to districts. To complement this decentralization process, the NAC has been working since early 2000 to improve the capacity of district AIDS coordinating committees (DACCs) in the planning and oversight of HIV interventions. This process has not been completed. However, significant progress has been made as evidenced by the placement of a District HIV/AIDS Coordinator in all Assemblies (districts) in Malawi. The challenge is to ensure that this new position is integrated within the district assembly structure.

The NAC is also working to decentralize the monitoring and evaluation system, and create evaluation units in district and city assemblies. "All district based HIV data will soon be collected and processed at that level, and NAC will at this stage only compile a national picture of the epidemic by consolidating all district HIV and AIDS data for a given period."

*"The UNGASS reporting process has been integrated into the national M&E framework, thus reporting on the UNGASS indicators will be 'business as usual' for Malawi in the future."*³⁶

The GOM submitted its first UNGASS report in 2003. In addition to providing information on in-

dicators tracked and progress achieved, the report also included a description of the preparation and consultation process for developing the national report. Civil society organizations, ministries, UN Organizations, the private sector, and bilateral donors were among the organizations providing input. In 2005, the GOM submitted its second UNGASS report. The UNGASS reports provide key challenges and identify gaps in the achievement of national goals. From feedback received by the government, UNAIDS, MANET+, and MANASO, the USAID-funded POLICY project was cited for providing the technical support needed to implement GIPA and monitor UNGASS.

COLLABORATION BETWEEN GOVERNMENT AND CIVIL SOCIETY

"The UNGASS reporting process is being viewed as one of the effective tools for citizens to hold their governments accountable for the commitments they have made on HIV and AIDS. Malawi has created various platforms for input into the UNGASS reporting process."³⁷

Although civil society was involved in the national review process in 2005, youth and PLHIV were largely represented by national organizations (which have local partners/networks/affiliates) such as NAPHAM, MANET+, and MANASO.³⁸ The CBOs that were interviewed felt that they could raise issues (i.e. advocacy issues, challenges to implementation, or need for services) with NAC, either directly or through MANASO.

The NAC invited civil society organizations to the National Progress Report Meeting, during which presentations were made on the 2005 report and civil society was invited to provide input. More than 350 participants representing civil society, public sector, and private sector attended, though not all organizations realized that it was the National Progress Report meeting. When asked if they were aware of the National Progress Report Meeting, only the organizations working nationally answered "yes", while the CBOs answered "no". The CBOs were not familiar with the national UNGASS review process, but they were aware that NAC collected data from all organizations carrying out HIV/AIDS activities. Some were aware the NAC held a national annual M&E meeting.

35 UNGASS Monitoring Civil Society Perspectives Malawi, Panos Southern Africa.

36 Follow-Up to the Declaration of Commitment on HIV/AIDS (UNGASS), Country Report for Malawi, 2003.

37 Annual HIV and AIDS Monitoring and Evaluation Report 2003.

38 For more details on the process refer to the Annual HIV and AIDS Monitoring and Evaluation Report for Malawi and the Country Report for Malawi on the 2003 UNGASS Process and the Country Report for Malawi on the 2005 UNGASS Process.

The national M&E framework for Malawi includes the UNGASS indicators, and all the organizations interviewed were aware that the NAC held annual monitoring meetings. Due to time constraints during the 2005 process, civil society was not asked to review and comment on the final national progress report. Technical assistance was provided in revising the draft report, and input was also sought from MOH and UNAIDS.

Only a few of the civil society organizations interviewed were aware of a parallel process for civil society to submit information directly to UNAIDS, though most, when asked, acknowledged that PANOS did a civil society review. Most organizations felt that the national review process was consultative, while a few felt it to be passive.

Other issues

KNOWLEDGE OF UNGASS, GIPA, AND THE CODE OF GOOD PRACTICE

Some of the community-based organizations interviewed were not aware of or had very limited knowledge of UNGASS, GIPA, or the Code of Good Practice. They stated that they did not use UNGASS commitments and GIPA to shape their programming. However, when asked if they were aware of the national reports for NAC and the national M&E framework, they answered affirmatively.

Perhaps raising awareness that the UNGASS indicators are part of a national framework would be beneficial, as most organizations were not aware they were reporting against these benchmarks. It is also important to note that the smaller CBOs largely receive information through NAC and national civil society organizations like MANASO and MANET+.

LINKS TO PROCESSES AND DOCUMENTS

The GOM, NAC and MANASO developed the "Stop AIDS Keep the Promise" Information Pack for the World AIDS Campaign 2005. The information packet included contributions to the Declaration of Commitment on HIV/AIDS in Malawi from 2001-2005. It summarized the progress made under the six pillars in the UNGASS: *leadership, prevention, care, support and treatment, human rights, research and resources*. The information also identified what needed to be strengthened in order

to stop AIDS and keep the promise to meet the UNGASS commitments.

Finally, under each pillar a series of questions were listed so that individuals (at national, district, and community levels) could ask themselves to gauge their level of engagement. For example, the leadership questions were directed to leaders at the cabinet level, members of parliament, community leaders, faith leaders, and traditional leaders. Some of the organizations interviewed cited this information packet and the World AIDS Day campaign as an example of how the government provides information on UNGASS outside of the national review process.

The Malawi Ministry of Agriculture, Irrigation and Food Security developed the "*HIV/AIDS in the Agricultural Sector: Policy and Strategy, 2003-2008*." GIPA and UNGASS were clearly reflected in the policy and strategy for the agricultural sector. This serves as the guiding document, in terms of the strategic pillars in the AIDS response. The Ministry is directly interacting with CBOs and has invited civil society, private sector, and the public sector to participate in the agriculture sector's HIV response. The Ministry is advocating for participatory rural approaches from the development of an action plan to implementation, as most organizations are agricultural-based.

The key to the national AIDS response in Malawi is the meaningful participation of PLHIV to centrally engage and assume leadership roles in all phases of the response. NAPHAM's membership and staff comprise of at least 95% PLHIV and NAPHAM is implementing activities in support of the National AIDS Framework, which is built upon the UNGASS principles. MANET+ is playing a critical role in promoting the six key pillars in the UNGASS. MANET+ is at the forefront of advocating for the greater involvement of people living with HIV/AIDS in Malawi. Specifically, MANET+ has a program on GIPA with a responsible program officer to advocate for GIPA at the national level.

Conclusions and recommendations

In general, respondents interviewed felt that civil society was engaged in the national review process and in the national response. Civil society organizations working at the national level in Malawi were

aware and consulted. However, both government and civil organizations interviewed felt more could be done to improve the national review process and civil society participation. Among improvements cited, was the need for more frequent national review meetings. More meetings would allow for sufficient time to review the final national review report. This would also ensure that contributions made by civil society organizations during the review meetings are utilized.

Most respondents also felt that more could be done to improve coordination and engagement of civil society, especially at the district level. In responding to the HIV/AIDS epidemic, the GOM has demonstrated political commitment at the national, regional, and district levels. The government's response has been greatly enhanced by the effort of development partners who have provided funding for both governmental and non-governmental programs. As a result, many civil society organizations carry out programs to mitigate the HIV/AIDS epidemic. However, there are still challenges in coordinating HIV/AIDS activities amongst NGOs, FBOs and CBOs in rural areas. Some NGOs do not feel obligated to report to the district assembly, and most of the District AIDS Coordinating Committees do not have sufficient capacity to coordinate the activities at district level. There is a need for improved coordination between civil society and government at the district level as *"the national response hinges on the success at the district level."*⁴⁰

The key challenges identified in the UNGASS reports are largely consistent with the barriers to participation identified by civil society organizations, some of which include:

- ✘ lack of capacity of organizations to apply for funds to engage in advocacy, conduct M&E, and successfully implement HIV programs; and
- ✘ lack of direct involvement of youth, women, and PLHIV in the national response.

Successful advocacy activities require the participation of a broad range of actors from all levels – civil society, government, donors, international communities and networks, faith communities, and the private sector. Malawi has several civil society groups that serve as national coordinating organizations for PLHIV support groups or AIDS service

organizations, (such as MANET+ and MANASO). They are responsible for advocating for HIV services and greater involvement of PLHIV. However, many civil society organizations, especially at the district level, lack the capacity to advocate for progressive HIV and AIDS programs. Many of these civil society organizations need capacity building assistance with regard to strategic planning, program design and development, resource mobilization, and advocacy in AIDS. Enhancing the skills of these organizations is particularly important because they reach diverse audiences throughout Malawi. This will help ensure PLHIV are more actively involved in the UNGASS national review process.

Although the National HIV/AIDS Policy has a focus on youth-related reproductive health issues and needs, young people need to be more effectively included as part of the response to HIV in Malawi. Increased participation of youth and youth organizations is also needed in the national review process. "According to an observation made by several other youth NGOs, it has been observed that there is consideration of youth participation in a number of programs, however, not so much consideration is put on youth participation in government activities at a higher level, especially in this case HIV/AIDS. There could be numerous benefits to society if youth were more involved, engaged."⁴¹

It is worth mentioning that youth activities need to be properly coordinated, as most of these groups lack capacity. "Youth-led initiatives should be considered in UNGASS to improve the flow of information at all levels for effective coordination and collaboration between the government and youth NGOs."⁴²

Stigma continues to be a barrier to civil society participation and must be addressed since it prevents PLHIV from being empowered and involved in Malawi's UNGASS review response. Initiatives aimed at reducing the prevailing climate of stigma and discrimination should focus more on the creation of nondiscriminatory and supportive national policies. While this is an important component, policy alone cannot stem the tide of AIDS stigma and discrimination, much of which has been internalized by PLHIV. Ensuring more public awareness of UNGASS and GIPA in Malawi will help to address this issue.

Emphasizing the links between the national M&E framework and UNGASS would help enhance un-

40 Quote taken from Interviewee's answer in Survey to "How can links between government and civil society be improved for UNGASS monitoring and reporting?"

41 Ibid.

42 Ibid.

Understanding and awareness about UNGASS. Some organizations interviewed suggested that the NAC data reports should be mandatory for all organizations carrying out HIV programming in Malawi. Rather than only providing information and holding meetings during the national review process or on World AIDS Day, information on UNGASS achievements and progress should be widely circulated and made a part of local responses.

Although all of the interviews occurred in the Lilongwe district, the organizations operating in the rural areas had very limited or no knowledge of UNGASS, GIPA, and the Code of Good Practice. "Most organizations do not have adequate information about UNGASS and its objectives. Making available such information would make them interested and possibly make greater contributions."⁴³ Thus, it is important that information packets in appropriate languages be shared with grassroots CBOs so they become more aware of the national strategic framework, UNGASS, GIPA, and the Code of Good Practice.

Recommendations for improvement

- ⌘ **Hold more frequent participatory review meetings** - Respondents cited that national review meetings were only held prior to release of national review reports and annual review reports. Having meetings on a quarterly basis, or even a semi-annual basis, would enable more interaction and participation from civil society organizations.
- ⌘ **Allow more time for the review of the final report** - More frequent participatory review meetings in advance would allow sufficient time for civil society and other stakeholders to provide feedback and input to the reviews and annual reports before they are finalized.
- ⌘ **Continue to encourage organizations to submit progress reports on achievement of UNGASS indicators** - Since progress reports are only required by organizations who are funded by the NAC, every organization who is carrying out HIV/AIDS programs should be required to file a copy of their M&E reports with the NAC.
- ⌘ **Conduct joint program design and planning with clear UNGASS M&E indicators is in the interest of both government and civil society** - Particular emphasis should be placed at the district levels to ensure that national M&E indicators are incorporated and tracked. International partners could provide assistance for holding review sessions and M&E capacity strengthening between civil society organizations and government operating at the district and local levels.
- ⌘ **Promote UNGASS through the partnerships and technical working groups** - This would provide an opportunity for government and civil society to work in partnership beyond the national review process. The various fora will help all parties explore ways to address barriers and challenges to achieving UNGASS goals as identified in the national reports.
- ⌘ **Establish awareness campaigns on UNGASS** - The establishment of awareness campaigns on UNGASS nationally in Malawi, and in particular at the district level, should be supported to enhance participation in the UNGASS national review process. Campaigns will also raise general awareness on Malawi's achievement towards UNGASS. The campaigns should be carried out by the NAC, in partnership with the civil society organizations who participated in the national review process. ■

43 Response from interviewee to the question on the survey "What could you do to be better involved?"

THAILAND

Summary

Among the countries in Southeast Asia, Thailand has experienced some of the more serious impacts of the AIDS epidemic since the first case was reported in 1984. As of February 2006, 81,176 persons have died from AIDS⁴⁴ in Thailand, and it is estimated that there are cumulatively over one million PLHIV. The most common route of HIV transmission is unprotected sex; most people are between the ages of 20 to 39 years at infection.

The first reports of AIDS in Thailand in the mid-1980s were among men who had sex with men (MSM). Then in 1988 cases were identified among Bangkok's heroin injecting drug users (IDUs) while in prison and/or in their home communities. A separate epidemic erupted one year later among female brothel workers and their clients in Chiang Mai, after which HIV spread widely throughout Thailand by men who bought sex. HIV was also transmitted to their wives and regular sex partners, and subsequently, to their children through pregnancy.

Despite the rapid spread of HIV, the Thai response is considered one of the more successful in the world. HIV incidence has been declining in most of the monitored populations since 1993 because Thailand has shown strong leadership in the fight against the epidemic. For example, Thailand is one of the first countries in the world in which the Head of State was also the chairperson of the National AIDS Committee (NAC).

The current composition of the National AIDS Committee contains senior representatives from key ministries including Public Health, Interior, Education, Vocational Development, Social Welfare, and representatives from PLHIV groups and the HIV NGO community. The Chairperson of the National Committee remains the Prime Minister, and the Secretariat of the NAC is the responsibility of the Center for AIDS Prevention and Promotion Alleviation Administration (CAPA). CAPA is also the focal point for coordinating the response to UNGASS policies, and for reporting progress toward the UNGASS country-level indicators for HIV formally submitted to UNAIDS.

In the previous report concerning Thailand's progress towards achieving the UNGASS DoC (2004-2005), CAPA contracted the services of a techni-

cal specialist from the Faculty of Public Health at Mahidol University. CAPA facilitated contacts, communications and meetings for the consultant with the relevant agencies. CAPA then synthesized the findings into a report for the NAC subcommittee on coordination, planning, budgeting, and evaluation to review and approve the findings before formally submitting them to the NAC.

Despite this apparently transparent and inclusive process, responses to this assessment indicated that key individuals in both the government and civil society involved in HIV/AIDS have very little awareness of past progress toward UNGASS indicators. Only a few were aware of the DoC. Instead, most respondents said that they were more concerned about the indicators and targets agreed upon with their respective donor agencies. This means that they monitored and reported progress toward donor agreements, which are not always aligned to the UNGASS indicators.

Even though Thailand has been able to submit reports to UNAIDS on its progress, most survey respondents from civil society agencies said they had no awareness that such a report was prepared or submitted. They also reported that they were not aware of the government agencies or individuals responsible for collecting the supporting data for the report.

Because civil society was largely left out of the process, most of the respondents to this assessment were not able to answer many of the questions in the survey instrument. Therefore, the conclusion from this survey indicated that civil society participation in the UNGASS reporting process was at the level of "passive involvement". The Thai government was the primary monitor and respondent regarding progress toward UNGASS targets. Further results indicated that previous reports of progress submitted to UNAIDS were not shared with many of the key government or civil society agencies.

Sampling

During the assessment, government and civil society provided a high level of cooperation. The sampling was conducted by referral beginning with CAPA, Raks Thai Foundation (CARE Thailand) and the Thai NGO Coalition on AIDS. Other groups were approached based on referrals from these organizations. UNAIDS was also contacted for referrals.

44 Center for Epidemiological Statistics, Bureau of Epidemiology, Department of Disease Control, Ministry of Public Health, Thailand.

Results

The current composition of the NAC contains senior representatives from key ministries including public health, interior, education, vocational development, social welfare, and representatives from PLHIV groups and the HIV NGO community. While the chairperson of the national committee remains the Prime Minister in name, his Deputy for Public Health actually chairs the meetings. Under the NAC there are three sub-committees including: (1) coordination, planning, budgeting, monitoring and evaluation; (2) provincial AIDS control; and (3) AIDS vaccine trials. The first two sub-committees include representatives from the key ministries represented in the NAC, while the third sub-committee is mostly comprised of medical personnel and clinicians. All three sub-committees have representatives from PLHIV groups and HIV NGOs. Formal coordination, joint planning, and monitoring between government and civil society entities occurs through scheduled meetings of the sub-committees or at *ad hoc* sessions on special issues.

The Center for AIDS Prevention and Promotion Alleviation Administration (CAPA) is the Secretariat for the NAC and is situated in the Bureau for AIDS, Tuberculosis, and Sexually Transmitted Infections of the Department for Disease Control of the Ministry of Public Health (MOPH). The role of CAPA in support of the NAC is to prepare the agenda for meetings and to transmit the proceedings of the NAC to the relevant agencies and individuals to ensure effective implementation of national policy and guidance.

OVERVIEW OF THE PROCESS IN THAILAND

CAPA is the focal agency for coordinating data collection concerning the country's response on progress toward the UNGASS indicators. CAPA is also responsible for producing and submitting the progress reports to UNAIDS. Soon after the UNGASS 2001, the MOPH convened a meeting of key government and civil society agencies involved in HIV to review and discuss the UNGASS indicators. MOPH requested the cooperation of certain civil society members with regard to collecting data to measure performance towards achieving the UNGASS DoC.

CAPA contracted the services of a consultant from the Faculty of Public Health of Mahidol University to assemble and analyze data and prepare the UNGASS report. CAPA provided support by providing contacts with the relevant government and civil

society partners, convening meetings as needed, and preparing a synthesis of the findings for the NAC sub-committee on coordination, planning, budgeting, monitoring and evaluation. After final revisions, the report was submitted to the entire NAC for acknowledgement. It is important to note that not all of the responsible officials interviewed during this assessment agreed with the strategy to hire a consultant to single-handedly implement the entire process of data collection, analysis and report writing. Instead, they felt it would have been more appropriate to use a consultant for certain components of the report preparation; for example, for the data analysis or narrative sections.

In general, the CAPA authorities indicated they were satisfied with the results of past progress reports. They felt the results showed that the Thai achievements were comprehensive in coverage. Progress for some groups were under-represented (e.g. orphans and other vulnerable children affected by AIDS) due to a paucity of information.

To facilitate the process of data collection for the current UNGASS progress report, CAPA added agenda items at various national planning meetings with government and civil society agencies. Meeting participants were thus not always fully aware that the information requested was for reporting progress toward the UNGASS indicators, as the meeting organizers did not always indicate the purpose of the data collection. CAPA filtered the responses to resolve inconsistencies or conflicting information; and relied on data from the Bureau of Epidemiology at the MOPH. Finally, CAPA submitted a draft report to the NAC sub-committee for review and editing before submitting the final report to the NAC for formal clearance.

CAPA was extremely pleased with the support they received from UNAIDS, especially the financial support, which helped to facilitate the tracking of progress toward the UNGASS indicators. The support from UNAIDS also provided a more flexible and rapid response, which may not have been possible if Thai government funds had been used. UNAIDS also provided support through the computerized Country Report Response System (CRIS), which facilitated data collection and organization. However, the UNAIDS representative felt that there were only a select few in the MOPH who knew how to operate the CRIS package program. The CRIS is only helpful in summarizing the HIV and AIDS data, not in the data collection or analysis.

COLLABORATION BETWEEN GOVERNMENT AND CIVIL SOCIETY

Thailand has a long history of government/civil society collaboration, pre-dating the UNGASS General Assembly in 2001. As Thailand was one of the pioneers of a comprehensive multi-sectoral response to AIDS, most of the Thai experience is consistent with the UN Declaration of Commitment on HIV/AIDS. Nevertheless, some activities have not been adequately documented or are difficult to document, such as work with hard-to-reach populations, including MSMs who do not self-identify, IDUs and highly mobile populations such as internally displaced persons (IDP) and migrant laborers.

The principle government agency in Thailand responsible for HIV is the MOPH. It is supported by other key ministries, including the Ministry of Social Development and Human Security, the Ministry of Education, and the Ministry of Labor. Programs and services for special populations such as PLHIV support groups, in-school youth groups, migrant labor populations, and others are supported by these line ministries. Most of the information needed for reporting progress against the UNGASS indicators is available in the various databases of the MOPH and other sectoral ministries.

For the most of the hard-to-reach populations, the national HIV program relies on the flexibility and outreach efforts of civil society organizations. Therefore, it is critical that government and civil society coordinate in order to develop a more complete understanding of coverage and progress toward the UNGASS indicators. This is especially true for those civil society organizations with access to the hard-to-reach individuals affected by the epidemic.

During interviews with civil society organizations, respondents were asked if they felt they were a part of the process of national monitoring of progress. Most of the respondents were unaware that a report to UNGASS was ever completed. Even the Thai PLHIV Network and the Thai NGO Coalition (both of which are represented on the NAC) responded that they had never heard about a report on progress toward UNGASS indicators submitted to UNAIDS. Most civil society agencies interviewed for this survey said they had never heard of the UNGASS progress report. At most, they were aware of the need to submit data on activities to the Department of Disease Control and assumed that these data were used to inform the national planning process.

They were not aware that any of the data submitted to the government was to be used for reports on progress toward the UNGASS indicators.

There may be some reporting bias in the survey, since information was sometimes "compartmentalized" between different staff members. As an example, the chairpersons of both TNCA and TNP+ were actually present in the meetings where the CAPA indicated that UNGASS reporting was discussed.⁴⁵ Often information does not always circulate well, and not everyone is clearly aware of what is going on, or why. In general civil society concluded that they did not fully participate in the process of preparing inputs for the UNGASS report. Their interpretation was that the process was managed solely by the government (i.e. "passive involvement"), as is summarized in the following table.

Table 3 Thailand – Civil society agency perception of the level of participation in preparing the progress report on UNGASS indicators

Perceived level of involvement	Number of respondents
Interactive involvement	0
Functional involvement	1
Consultative involvement	2
Passive involvement	7
Total	10

It should be noted that the CAPA is trying to somewhat rectify this by holding consultations with a broad range of stakeholders before the Thai UNGASS delegation goes to New York. Some civil society agencies receiving funding from the Global Fund against AIDS, TB and Malaria (GFATM), such as the Raks Thai Foundation and the Thai Business Coalition on AIDS, were aware that information was being collected by the MOPH for reporting progress toward UNGASS indicators. These two agencies actively provided data on coverage and HIV activities for their respective beneficiary populations, including migrant laborers and the private sector. Only one agency felt they had been functionally involved in preparing responses to UNAIDS against UNGASS indicators.

In parallel, other civil society agencies, some of whom also received grants from the GFATM, were not informed of the UNGASS reporting process.

45 As reported by the UNAIDS Representative in Thailand, April 2006.

These agencies include the AIDS Foundation of Thailand, which focuses on prevention of mother-to-child transmission of HIV. It is possible that the relevant data on their activities were already available in the MOPH database through routine reporting channels.

Overall, the UNAIDS representative felt that the level of civil society participation was “consultative” at best. This view was echoed by many of the respondents from civil society agencies who did not feel that the nature of the collaboration between government and civil society was fully participatory.

Other issues

GIPA PRINCIPLE

At present, PLHIV have an important role in the delivery of HIV services in prevention, care, and treatment in Thailand. PLHIV are active as peer educators, counselors, resource persons, and public speakers on prevention. Thai PLHIV also play a role in offering opinions and advice on national HIV strategies.

As previously mentioned, PLHIV are represented on Thailand’s National AIDS Committee. In some provinces, PLHIV function as pre- and post-test counselors at HIV testing centers. The active involvement of PLHIV in these services can be traced back to the development of support groups. At present there are PLHIV support groups in every district in Thailand. These groups are then linked by networks at provincial, regional, and national levels.

This mobilization of PLHIV has resulted in their active contribution to HIV activities at the local and national levels. Because these support groups emerged as an indigenous response, they are not necessarily familiar with the standards and guidance from the Greater Involvement of People Living with HIV/AIDS (GIPA) Principle. There was little awareness of the role or activities of GIPA among government and civil society respondents in this assessment. Those that had heard of GIPA had only heard it mentioned at international AIDS conferences.

Conclusions and recommendations

The results of this assessment for involving civil society in country-level UNGASS processes led to the following findings and recommendations:

⌘ **Knowledge of the Declaration of Commitment on HIV/AIDS (DoC)** – Nearly all of the civil society respondents to this assessment had not heard of the DoC. Thus, respondents were not sure how to address related questions. In 2005, the government translated a copy of the DoC into Thai, and printed 3,000 copies for distribution. However, only a minority of civil society agencies received the Thai version. Unless there is a more complete dissemination of the DoC and subsequent reports, civil society organizations will not be able to fully respond to or report against the call for commitment.

⌘ Communicating and sharing information

The government and international AIDS agencies did not adequately or completely inform local civil society about their international role in reporting as part of the UNGASS national review process. It was perceived that this was especially true for organizations working outside of Bangkok. Also, many of the respondents were unaware of international standards or guidance such as the GIPA Principle and the Code of Good Practice for NGOs Responding to HIV/AIDS.

A forum should always be arranged with the relevant HIV/AIDS agencies to explain the background of UNGASS and its importance to the national program; to explain the progress reporting process – past, present, and future; and to define the UNGASS indicators and targets. The organizers of the forum should disseminate key background documents such as the *Declaration of Commitment on HIV/AIDS* and the full list of UNGASS indicators in such a way that they reach all agencies and organizations that need to be included in the process and consultation.

⌘ **Reporting** – Prior to implementing the data collection for each round of reporting progress toward the UNGASS indicators, the responsible agency needs to inform all the relevant government and civil society organizations of the objectives, methods, and time frame for conducting the data collection. Opportunities must be provided to allow the collaborating agencies to participate fully at all stages of the process.

⌘ Lack of harmonization and M&E coordination

– Most organizations working on HIV/AIDS in Thailand are accustomed to the indicators and achievement targets negotiated with their donor agencies. Not all donors align their targets with UNGASS. This creates a diverse and non-stan-

standardized set of indicators that are used by organizations throughout the country. Some of these indicators may be identical to those promoted by UNGASS, but many are likely to be different. The government must work with donors to create a harmonized approach to monitoring, evaluating, and reporting. Donors should also provide support for M&E capacity strengthening and participatory methods in order to strengthening reporting and partnership between government and civil society.

The Bureau of AIDS, Tuberculosis, and Sexually Transmitted Infections (the government agency responsible for assembling the report on progress toward the UNGASS indicators) has not adequately explained the process of monitoring progress toward the UNGASS indicators to the relevant agencies and organizations in both government and civil society. Most of the civil society organizations surveyed (including agencies with representation on the NAC) were unaware that there was a process for reporting to UNAIDS.

The government agency responsible for facilitating the data collection for the report prepared by the AIDS Bureau (CAPA) was also not fully familiar with the process of preparing progress reports based on the UNGASS indicators. Instead, CAPA was only familiar with the data that are routinely forwarded to them directly (or to the AIDS Bureau). Thus, it is not surprising that most of the respondents to this survey were not aware of the UNGASS progress reporting requirements. In turn, they could not answer most of the questions about participating in the process so they perceived their level of involvement to be merely passive.

- ⌘ **Meaningful participation** – Despite civil society input into previous progress reports, several respondents felt that their involvement was *ad hoc* and merely representational. It was suggested that civil society be involved in partnerships with government throughout all stages of design, implementation, monitoring, evaluating, and reporting to ensure meaningful participation. It was also noted that the government rarely, if ever, reports back to civil society on the

final product of the data gathering, how it was reported, to whom, etc. This causes a lack of confidence from civil society regarding whether the data they provide is used, whether it is used properly and whether it is correctly interpreted.

The government needs to reconsider its strategy for promoting partnership with civil society organizations engaged in HIV. The optimal strategy will be one in which there is mutual satisfaction with the process and results in a sense of teamwork. Even though the government might feel satisfied with the progress and collaboration to date, this assessment shows that civil society has reservations about the level of access and information that the government is willing to provide. While civil society recognizes that collaborative action is a national responsibility, it appears that the level of collaboration varies depending on personal connections between individuals in government, and with certain civil society organizations.

- ⌘ **Review process** – The government office responsible for producing the UNGASS national review did not share the report with other government offices and civil society organizations providing data. This prevented the opportunity for the participating agencies to review and provide recommendations regarding the entire report. In the future, UNAIDS and other donors could work closely with the government to ensure that an effective review processes and systems are in place.

To facilitate discussion of findings and to ensure participation by relevant organizations, the responsible agency should convene a forum to present the results of the data collection on progress toward the UNGASS indicators, and to invite comment and observation on the findings. Because these are national findings to be reported internationally, the forum should be national and well-represented. It would also be an opportunity to remind agencies to implement their programs in accordance with national priorities as stipulated by the NAC. This forum would not only inform civil society about the DoC, but would also be an opportunity to discuss national priorities, lessons learned, and progress made.

<i>Name of project:</i>	Prevention of Mother-to-Child Transmission (PMTCT)
<i>Implementing agency:</i>	Department of Health, MOPH
<i>Source of funding:</i>	Government of Thailand
<i>Duration of implementation:</i>	National coverage since the Year 2000

Collaboration between government and civil society: The government and civil society collaborate on this project through PLHIV support groups and the government hospital (at the district level). In most cases, groups of (predominantly) female PLHIV play an important role in home visits with pregnant women, new mothers and infants. The home visits encourage the participants to keep a regular schedule with medical check-ups at the community hospital. The members of the support group are also trained to provide effective peer counseling and support to the new or expectant mothers.

After a pregnant woman registers for ante-natal care at a community hospital, she will receive pre-test counseling before an HIV diagnostic test is administered. The HIV test is voluntary. In a small number of hospitals, some of the women who are HIV-positive are trained to be peer counselors and provide pre-test counseling for other women coming for ante-natal care. In cases where the test is HIV-positive, post-test counseling is provided (usually by a nurse). At this session, the HIV-positive woman is asked if she wants support from other HIV-positive women who have come for ante-natal care. If she does, the nurse will introduce her to the support group of HIV-positive mothers.

Currently, nearly every district in Thailand has these support groups. Members of the support group will ask the HIV-positive woman if they can visit her home on occasion both before and after delivery. This step is crucial in assuring consistent follow-up with the HIV-positive mother and her child. This link with the HIV-positive mother through the PLHIV support group significantly increases the ability of the hospital to provide a continuum of care, and maintain complete data for the HIV-positive mother. Prior to the involvement of the support groups, hospitals were not very successful in providing the necessary support to these women.

General nature of target area and population:

Even though the national HIV prevention program was able to reverse the incidence of infection among some high risk populations, among pregnant women the rates were still increasing. This had implications for the rate of pediatric AIDS, with the probability of vertical transmission at 30%. The MOPH developed a pilot project to reduce the rate of mother-to-child transmission, which has since scaled up activities to achieve national coverage.

Activities of the project: The PMTCT project provides AZT to pregnant women infected with HIV and to the child at birth. The MOPH model project was first piloted in 1997 in the upper southern and north-east districts. The project was expanded to national coverage three years later. All pregnant women receive HIV pre-test counseling and screening on a voluntary basis, and those found to be infected receive anti-retroviral prophylaxis treatment during pregnancy and at delivery. All infants born to HIV-positive mothers receive anti-retroviral prophylaxis treatment, a supply of infant formula and HIV diagnostic tests. The mother, child, and HIV-positive father of the child are also able to receive monitoring and care as needed.

An evaluation of the PMTCT program in 2002 found that 97% of pregnant women who intended to deliver at a government hospital received ante-natal care. A total of 96.5% received counseling and screening for HIV. Of the total tested, 1.1% was found to be HIV-positive and 63.6% of these women received AZT prophylaxis.

Future plans: At present, the Department of Health has received financial support from the Thailand Ministry of Public Health and the US Centers for Disease Control and Prevention (TUC) to develop a computerized package program entitled *Public Health Information Management System (PHIMS)* to help compile data on the PMTCT program. The database will also provide the input necessary for producing the national report on progress toward the UNGASS indicators. At present, the Department of Health and the TUC are developing a second package program called CHILD, which will record data on infants enrolled in the PMTCT program and provide data input needs for the UNGASS report.

Impact of the project: The PMTCT program has helped reduce the rate of vertical transmission of HIV in Thailand by 30%. Currently, there is approximately an 8% risk of MTCT and this project has averted an estimated annual 2,225 pediatric infections.

Lessons learned: When the pilot project first began, a number of women were lost to follow-up after delivery at the community hospital, reducing the coverage of the PMTCT activity. However, after the active involvement of the PLHIV support groups, the number of post-partum women lost to follow-up was significantly reduced. ■

UNITED KINGDOM

Summary

In 2004, there were 58,000 people living with HIV in the United Kingdom out of a total population of 60 million. Of these, 45% were gay or bisexual men, 51% had been infected through heterosexual sex, and 3% through injecting drug use. African-born people account for 60% of heterosexuals living with HIV in the United Kingdom. People living with HIV are concentrated in London (around half) and to a lesser extent, around Edinburgh and Manchester.

The mode of transmission in the United Kingdom has changed from the 1990s. Initially gay and bisexual men constituted most of the people living with HIV, along with some men and women who became infected as a result of injecting drug use. Now, people of African origin – both men and women – form a separate and very significant group. Many of the civil society organizations responding to HIV have adapted their focus to accommodate this change. Others have chosen to focus on a particular group.

The United Kingdom government's national response to HIV has largely been to treat it as part of sexual health. Under the arrangements for devolved government in the United Kingdom, health and HIV are the responsibility of the four different health executives for England, Northern Ireland, Scotland and Wales. Each of these takes a slightly different approach. The United Kingdom Department for International Development (DFID) has made HIV a priority, providing significant funding and leadership to the international response. It is important to note, however, that the United Kingdom does not have a national HIV strategy.

This assessment was conducted in the United Kingdom to obtain information from representatives of two government departments – Health and International Development – and twelve civil society organizations. This was primarily through face-to-face interviews with London-based organizations, and telephone interviews with others (in Manchester and Edinburgh.) The civil society organizations chosen were national, regional and international organizations.

The Department of Health for England took responsibility for the United Kingdom government's report for UNGASS 2006. In early December 2005, it asked four national organizations to work over 12 days to draft the part of the UNGASS report that related to civil society. Three collaborated and sub-

mitted a draft in mid-December. In January 2006, the Department of Health posted its full interim report for UNGASS on its website, along with a request to provide comments by mid-April 2006. The consultation was limited to receiving submissions electronically. There was little outreach to inform or consult civil society. Factors contributing to the process being handled in such a manner include that the official responsible did not receive detailed information from UNAIDS until November, and there was also a low priority given to the report in the face of other demands and limited resources.

Some nationally-focused civil society organizations contributed to the United Kingdom interim report. All planned to use the opportunity of the consultation to register concerns relative to government policy and practice. However, there was not a lot of enthusiasm for the UNGASS consultation. The report document was seen as dry and remote, the language used did not encourage involvement, and the prescribed questions did not fit civil society priorities. UNGASS was viewed as moderately useful, rather than essential in terms of mechanisms to provide leverage for policy concerns. A consistent comment was that for a meaningful process more time should have been provided. There was some concern that the approach used was directive, and controlled by the Department of Health, leaving little scope for civil society to participate in the process in a meaningful way.

All regional civil society organizations contacted knew of the consultation process. However, none had heard directly from the Department of Health, but rather were informed through networks. The general view was that the UNGASS consultation was not a priority in the face of conflicting demands. Organizations were willing to contribute, but not to invest too much time. As with the national players, these organizations needed to be made aware of the relevance of the UNGASS report, and would have valued hearing about the consultation earlier.

The internationally-focused NGOs were frustrated that the United Kingdom process excluded them from commenting on Department for International Development (DFID)'s contribution to fulfilling the UNGASS commitments – despite DFID being a major international player in HIV. In response, the United Kingdom Consortium on AIDS and International Development (UK Consortium) liaised with the All Party Parliamentary Group on AIDS to hold a public meeting with officials of both the Department of Health and DFID. At this forum

it presented a “snapshot” of civil society perspectives on the government’s response both within the United Kingdom and internationally. The national players, and some of the regional players,

have well-developed policy analysis and influence skills. There is interest in using this to support advocacy partnerships with southern civil society organizations.

Canada’s process and report for UNGASS+5 – a comparative analysis

The Public Health Agency of Canada (PHAC) was the lead agency for developing the initial drafts of the Main Section, Part A of Annex 2 (the National Composite Policy Index). Annex 3 was prepared by PHAC in consultation with other government departments participating in the federal response to the AIDS epidemic. Representatives of the provinces and territories were also included in the process. In late November 2005, a draft was sent out for comment to key national partners, national NGOs, the Ministerial Council on HIV/AIDS, and the National Aboriginal Council on HIV/AIDS.

In January 2006, a teleconference was held with representatives of key national partners and government departments to review and discuss the findings of the entire report (including both parts of Annex 2) in order to: *address issues of consistency, accuracy and tone; ensure the document as a whole provided an accurate description of the Canadian response; and recommend a process for future UNGASS reporting.*

In a separate process, the PHAC contracted an external consultant to prepare Part B of Annex 2 (the National Composite Policy Index) concerning human rights and civil society participation, in consultation with national HIV/AIDS NGO and human rights experts. This draft document was sent to national HIV/AIDS NGOs for feedback and input. Part B of Annex 2 was not subject to changes by government as it was designed to be an independent document and reflective of civil society inputs. The Canadian report abandons the UNAIDS report template, and uses a much more readable and accessible approach. The report

also integrates Canada’s international HIV/AIDS responses with the national review:

“While this report focuses mainly on the domestic response, it is important to note that Canada is committed to helping global efforts to meet the UNGASS Commitments through our development assistance programs, contributions to global initiatives, and support given to policy development within global fora.”⁴⁶

What underlies this is a commitment to integrate HIV/AIDS national and international programs and policies:

“HIV/AIDS is clearly positioned as an important domestic and international issue for the federal government. The Federal Initiative coordinates the domestic response and also seeks to bridge the domestic and international responses. It is a horizontal initiative, involving four federal departments and agencies...The Canadian International Development Agency and Foreign Affairs Canada work together on the international response. The domestic and global responses are linked through various mechanisms to ensure policy coherence and shared learning.”⁴⁷

“The Federal Initiative builds on the previous Canadian Strategy on HIV/AIDS (1998-2004) and reinforces the importance of partnership and engagement with players across governments, civil society, health care providers, researchers, and those living with or at risk from HIV. It is an approach grounded in human rights and the determinants of health.”⁴⁸

46 Foreword Government of Canada Report to Secretary-General of the United Nations on the UNGASS Declaration of Commitment on HIV/AIDS. January 2003-December 2005.

47 Ibid, p. 21.

48 Ibid, p. 7.

Comparing the United Kingdom process to another northern UNGASS national review process, such as the Canadian process and report, provides a challenge to the United Kingdom government, particularly as the nature of the HIV epidemic in the two countries is very similar. The Canadian process was more inclusive, timelier, and external support was used to prepare a civil society report. The report also integrated Canada's domestic and international responses.

Sampling

An assessment was carried out in March 2006 through face-to-face interviews with London-based organizations and via telephone interviews with others in Manchester and Edinburgh. Initial contact was with the four well-known national-level organizations that contributed to the interim report. Policy staff from these organizations helped to identify other organizations, so that a range of organizations were contacted (see Appendix 2). In particular, the study ensured that the sample included organizations focusing on specific regions of the United Kingdom, and that women living with HIV were included in the study. The UK Consortium provided an entry point to organizations concerned with the international dimensions of the United Kingdom response. The list of participants was verified with interviewees to ensure that no organization that might be significant to the assessment was missed.

The sampling was designed to include organizations programming a comprehensive approach, and those that have a focus on either gay and bisexual men or Africans. It also included the one national organization with a focus on women living with HIV. Contact with government was limited to the Department of Health and the Department for International Development. Twelve civil society organizations were approached, making a total of fourteen interviews. Several of the questions in the interview questionnaire were irrelevant without a review process; therefore the questionnaire was not used in favor of a more open-ended process to elicit answers to four critical areas: understanding and use of UNGASS, GIPA and Code of Good Practice; experiences of the Department of Health's consultation, including the nature of the organization's participation; how participation could have been improved; and how organizations included the views of PLHIV.

Results

OVERVIEW OF THE PROCESS IN THE UNITED KINGDOM

Government responses to HIV within the United Kingdom reflect two key decisions. HIV was seen as a health issue - part of a broad response to sexual health. Devolution of government in the late 1990s meant that some functions were delegated to separate administrations in Scotland, Wales and Northern Ireland. Other functions stayed in the London (Westminster) United Kingdom government. This is similar to a federal system in some countries. Responsibilities for health responses were delegated allowing for different approaches; therefore there is no consistency in terms of strategies, regulations, and accountability.

There is no national AIDS commission, or multi-sectoral national AIDS strategy. This means there is no overarching plan for health and social care responses to HIV in the United Kingdom. Instead, responses to the epidemic fall into different "executives" in Scotland, Wales, Northern Ireland, and England. The Department of Health in London relates to the United Kingdom (Westminster) Parliament, as there is not a separate parliament for England. It also leads on United Kingdom-wide issues. Other government departments relate to the health agencies on an issue basis. For example, the Department for Education in England relates to the Department of Health in England around promoting sexual health in schools.

The United Kingdom has also been active in supporting international responses to HIV/AIDS. These responses fall under the leadership of DFID, for which HIV is a priority. In addition to making significant financial commitments (over £500 million per year since 2004), DFID has been a leading player in promoting progressive policies and approaches, including support for the Global Fund, the "Three Ones", and the Gleneagles G8 Declaration on Universal Access. Clare Short, who was the Secretary of State for International Development, also led the United Kingdom delegation to UNGASS in 2001.

The United Kingdom did not submit a report to UNGASS in 2003. This appears to have been due to confusion between DFID and the Department of Health as to whether the United Kingdom, as a low prevalence country, was supposed to submit a report, and if so, which Department was responsible. Therefore, the National AIDS Trust, a national

policy NGO, seized the opportunity. It published a shadow report highlighting what it saw as gaps in the United Kingdom government's domestic response to HIV/AIDS.⁴⁹

For UNGASS 2006, the Department of Health in London understood they had responsibility for compiling the report, with input from DFID, on behalf of the United Kingdom. However, there was confusion on where the reporting instructions should be sent. Because of this delay, data compilation did not begin until November. This rushed the process since it was difficult to coordinate inputs from the counterpart government agencies in Scotland, Wales and Northern Ireland with such short notice.

The Department of Health in London was also aware that they needed to receive inputs from civil society, particularly for the National Composite Policy Index (Part B).⁵⁰ Because of the short turnaround time, four national NGOs that engage in policy work⁵¹ were contacted to provide inputs through one coordinating agency – the Terrence Higgins Trust. This request did not reach the NGOs until 5 December 2005 with a deadline of 16 December. With so little time, the NGOs did not manage to meet face-to-face. Three NGOs liaised via e-mail and telephone, and agreed on a joint submission. The fourth NGO was not able to participate due to follow-up World AIDS Day activities. The joint submission formed the basis of the relevant section of the United Kingdom's report, which was submitted to UNAIDS as an interim report on 6 January 2006.

After submitting the interim report to UNAIDS, the Department of Health began to fill in gaps, and provide opportunities for wider input from civil society. A formal consultation process was launched on the interim report on 9 January 2006. This process followed the government's code of practice for consultations, which allows for a minimum period of 12 weeks. The formal process for consulting civil society thus ended 11 April 2006, and many civil society organizations were still working on their responses while the present assessment was being prepared.

Unfortunately, there is no active strategy to reach civil society, particularly beyond England (although officials in the other United Kingdom health execu-

tives have been consulted and encouraged to disseminate to relevant civil society organizations). No guidance is given on key questions⁵² or background to the report. The Department of Health expects only 10-15 civil society responses.

This approach is in contrast with the extensive consultation exercise surrounding the national strategy for sexual health and HIV in 2001, which included regional forums and support to NGOs. During this time, the Department received over 400 submissions. It was explained during the assessment that the difference in process was an outcome of competing priorities and resources. There is only one post and a half-time equivalent dealing with all policy work related to HIV in the Department of Health. In addition, due to the timing of UNGASS, the 1.5 staff had to manage the consultation in parallel with one on the Department's *Action Plan to Address HIV Stigma and Discrimination*, which was already planned. No funding was made available from government to hire consultants to support the UNGASS national review.

The assessment findings indicate that civil society organizations are concerned that government funding and support for sexual health in general, and HIV in particular, is insufficient. They feel that the lack of support is symptomatic of government attitudes, but that the Department of Health managed the best they could with the little resources provided for this activity.

COLLABORATION BETWEEN GOVERNMENT AND CIVIL SOCIETY

In approaching the United Kingdom report for UNGASS, civil society wanted to voice key issues. Their perception of a lack of coordination across government agencies was seen to be reflected in the approach to the reporting process. There was particular concern expressed by those interviewed that DFID did not participate in the national response, thus allowing no opportunity for DFID to present its contributions toward achieving the UNGASS commitments or for civil society to comment on what was drafted.

The assessment interviewees were part of three broad groups of civil society organizations:

49 http://www.nat.org.uk/Documents/UNGASS_REPORT.DoC

50 This is a prescribed section in the report. Covering questions under the topics: Human rights; civil society participation; Prevention, Care and Support. It comprises about a third of the report.

51 African HIV Policy Network, National AIDS Trust, Terrence Higgins Trust, UK Coalition of People Living with HIV/AIDS.

52 One issue that arose from interviews was that each respondent had a different interpretation of the intended framework for scoring the situation in 2003 and 2005 in the numerous tables, which ask this question. Some scored against how things could be in UK, others against how they perceive things are globally.

National organizations such as the National AIDS Trust (NAT), Terrence Higgins Trust (THT), UK Coalition of People Living with HIV/AIDS (UKC), and the African HIV Policy Network (AHPN). These are long-established, London-based, and have dedicated policy program capacity. Their policy work includes United Kingdom-wide issues, although they also focus on policy issues for England. Some are members of the UK Consortium on AIDS and International Development (UK Consortium) and lend support within the United Kingdom to advocate on international issues.

Regional service providers with some policy capacity are another group, and include organizations such as the George House Trust in North West England, HIV Scotland and Waverley Care in Edinburgh, and the Gay Men Fighting AIDS (GMFA) in London. These organizations are quite well established, but have varying capacity to engage in policy issues – usually through a staff member with other responsibilities. There is also some migration towards the national groups. For example, Positively Women was primarily a service-provider in London, but is now supporting positive women throughout the United Kingdom. Funding for this group comes from diverse sources, mostly for specific contracts dedicated toward service provision. The funding allocated for HIV Scotland’s policy work is notable as it comes with a stated expectation that HIV Scotland will provide a critical voice, and be a means for the views of PLHIV to be expressed.

Internationally-facing NGOs are the third group of organizations. Most of these groups support responses to HIV/AIDS in the South. Many have dedicated policy capacity to speak on international issues within the United Kingdom and internationally. They are part of the UK Consortium on AIDS and International Development (UK Consortium), which has over 80 members and a small secretariat. As well as working individually, these organizations work together very effectively on specific issues through advocacy efforts coordinated through the UK Consortium. Many of these NGOs have significant funding from the public, and institutional funding through a DFID PPA.⁵³ Because of their focus on international – as opposed to domestic – responses, they were largely excluded from the United Kingdom UNGASS process. As the assessment was conducted across all three groups, findings describing civil society perspectives are described separately.

As previously stated, the Department of Health approached these organizations to compile part of the United Kingdom interim report in January 2006. Some national groups commented that the draft report to date was dry and remote; the language used did not encourage involvement, and the prescribed questions did not fit civil society priorities. One organization commented that UNAIDS had not offered evidence as to why it was worthwhile engaging in the process.

Another stated that the Declaration was limited and did not provide the necessary “levers” for pressuring the government on specific issues. Another felt that the International AIDS Conference in Toronto, rather than the UNGASS meetings in New York, was the priority for 2006. Overall, UNGASS was viewed as moderately useful rather than essential. Possibly this is why these organizations were not too upset at the government’s process – for them, UNGASS did not appear sufficiently important to make a priority; there was little ownership.

An exception to the relatively low priority that civil society organizations gave to UNGASS was the UKAIDS and Human Rights Project (UKP). This project seeks to ensure that human rights are respected for those affected by HIV. The UKP is a registered charity in the UK that actively maintains a website, lobbies MPs over the UK UNGASS report, and submits shadow country reports now on the UNGASS website.⁵⁴ For the UKP, the United Kingdom government’s handling of the UNGASS reporting process is an opportunity to publicly challenge the government’s record on human rights for PLHIV and those affected by HIV.

No organization planned to consult with its stakeholders specifically on the UNGASS report. Instead, most submissions are being developed by staff. In general, organizations do try to draw upon the views of PLHIV in formulating their policy positions. Most organizations relate to service-providers who are in direct contact with PLHIV, as that might be a branch of the organization, or through a policy network that they have established. The UKC uses its activities to directly obtain the views of HIV-positive people through a national conference, and by running features in its *Positive Nation* magazine with requests for feedback. Positively Women has also recently appointed a Policy and Involvement Manager to enable positive women to speak out.

53 Program Partnership Agreement (PPA).

54 www.ungassshiv.org/index.php/ungass/ungass/shadowreports2006/other/united_kingdom

Other issues

NATIONAL ORGANIZATIONS - KNOWLEDGE OF UNGASS, GIPA, AND THE CODE OF GOOD PRACTICE

These organizations have a well developed understanding of UNGASS, and the relevant processes. There is, however, considerably less interest in UNGASS now than in 2001. Only two organizations planned to submit shadow reports to UNAIDS (NAT and UKP). Others were not aware of the possibility to do so.

Organizations were aware of GIPA, but had strikingly different interpretations of what it meant in practice – primarily these concerned whether GIPA emphasized the role of PLHIV, or recognized that PLHIV could have significant involvement in organizations providing services. This has been successful for groups like THT where a significant number of employees and board members are openly positive.

The only organizations that seemed to be aware of the *Code of Good Practice* were NAT and UKC, both of which are signatories.

REGIONAL ORGANIZATIONS - KNOWLEDGE OF UNGASS, GIPA, AND THE CODE OF GOOD PRACTICE

Generally, these organizations had limited knowledge of UNGASS – there was a vague awareness of a UN process. Only one had heard of GIPA as a formal concept, though most were concerned about ensuring the involvement of PLHIV in their organizations. None surveyed had heard of the Code of Good Practice.

All of the organizations had heard of the UNGASS national review consultation process. None had heard of the process directly from the Department of Health, however, but rather had gotten their information through networks and bulletins from United Kingdom national groups. AHPN had directly approached several groups for contributions to the UK Consortium's "snapshot" document.

Due to capacity constraints, these organizations prioritize their involvement in external consultations. Priority is given to issues that have the most direct relevance to the organizations' constituency. For example, HIV Scotland felt that UNGASS related to Westminster rather than to Scotland. It

also coincided with the consultation on stigma and discrimination, which was a higher priority for their Scottish constituents. The general view was that the UNGASS consultation was not a priority in the face of conflicting demands.

As with the national organizations, these organizations were not sufficiently aware of the relevance of their participation in the UNGASS report. None of these organizations intended to specifically consult PLHIV for the UNGASS report. In general, they sought to elicit the views of positive individuals through their contacts with service providers.

INTERNATIONAL NGOS - KNOWLEDGE OF UNGASS, GIPA, AND THE CODE OF GOOD PRACTICE

The UK Consortium members challenged DFID to be involved in the UK UNGASS report in November 2005, but were told that DFID's participation was not appropriate. These NGOs felt frustrated that the United Kingdom process excluded them from commenting on DFID's contribution to fulfilling the UNGASS commitments. In response, the UK Consortium liaised with the All Party Parliamentary Group on AIDS (a cross-party grouping of national parliamentarians) to hold a public meeting with officials of both the Department of Health and DFID. At this meeting a "snapshot" of civil society perspectives on the UK government's response both within UK and internationally was presented.

Conclusions and recommendations

It is concluded that the process implemented by the Department of Health did not adequately reflect the intent of Article 94 of the Declaration. There was no review, and only limited opportunities for civil society participation, especially with regard to the report preparation process. In this respect, the United Kingdom government report for UNGASS+5 will lack credibility. This may impact the United Kingdom government's (particularly DFID's) ability to advocate for other governments to comply with their commitments under the Declaration, especially in relation to working with civil society.

The United Kingdom national groups have a well-developed understanding of UNGASS and the relevance of its processes. They were aware of GIPA but had different interpretations of its implications. Very few were aware of the Code of Good Practice. Regional

organizations mostly had only a vague awareness of UNGASS. They had no awareness of GIPA as a formal concept or of the Code of Good Practice.

The following issues are recommendations provided after reviewing the feedback received from the respondents.

- ⌘ **Ensure meaningful involvement** – The government and UNAIDS need to ensure that all the relevant areas of the government are aware of the UNGASS national review processes, and their responsibilities for compiling the UK report. In order to comply with Article 94, the consultation process should enable the meaningful involvement of a range of civil society players from the outset. Additional resources should be made available to ensure this takes place.
- ⌘ **Allow time** – UNAIDS and the UK government must allow sufficient time to ensure comprehensive responses, especially when government is devolved and information is difficult to collect and review within very short time frames.
- ⌘ **Integrate national and international responses** – DFID needs to review how it may promote the participation of civil society emphasized in overseas programs given that the UK domestic process was not participative. UNAIDS should review the interpretation of Article 94, noting that it relates to progress on the commitments, which include Articles 79-93 related to funding. Future country report formats should request that the review include significant material on funding and other contributions to international responses.
- ⌘ **Increase ownership** – The relatively low priority given to UNGASS by civil society is of concern. More emphasis should be placed on advocacy and partnership efforts within the United Kingdom so that government and civil society own the UNGASS commitments and national review process. UNAIDS reporting documents need to have clear guidelines, and be flexible as concerns the particular needs of a country. ■

VIETNAM

Summary

HIV was first detected in Vietnam in December 1990 and has spread throughout the country despite national efforts to control the epidemic. Concentrated initially among injecting drug users, sex workers, and their clients, the epidemic is now spreading to the general population. Since 1999, more than 10,000 new HIV sero-positive cases have been reported annually. As of 31 October 2005, the cumulative number of PLHIV reported nationwide was 102,391, of whom as many as 16,917 had advanced to AIDS.

During the first 10 months of 2005, 12,011 people were newly diagnosed with HIV, of whom 2,489 had developed AIDS and 1,464 died.⁵⁵ Although injecting drug use remains the main route of transmission, accounting for 57% of all reported infections, sexual transmission has continued to increase.⁵⁶ Among reported cases the proportion of youth aged 20-29 has been increasing rapidly, from 15% in 1993 to 54.6% by mid-2004. UNAIDS warns that the epidemic could reach a generalized stage⁵⁷ if prevention efforts are not put aggressively into place.

Acknowledging the potential threat of the epidemic, the government of Vietnam has responded quickly, showing strong political commitment to HIV prevention and control by increasing the budget for the national program. There is also an increase in the visibility of high-ranking officials participating in the planning and implementation of HIV-related activities. The system for HIV prevention and control has been established from the central to grassroots level. Multi-sectoral approaches have been recommended and promoted, and civil society has been more and more active in participating in HIV/AIDS programs.

Vietnam endorsed the DoC. As part of this commitment, the government of Vietnam has submitted two national reports, one in 2003 and the second in January 2006. An assessment was conducted in order to explore the experiences of civil society organizations (CSOs) in the Country Level UNGASS 2006 Process in Vietnam. The survey aimed to identify lessons learned, gaps, and solutions for improving the participation of civil society in the national review process.

Sampling

The Vietnam Administration for AIDS Control was contacted to identify organizations that participated in the UNGASS review process 2006. All potential respondents were identified against the methodology document developed by the consultant for CARE International. However, some individuals who contributed to the UNGASS report 2006 were not available for the survey. As a result, only half of the respondents were actually involved in the national review process.

In Vietnam, 19 representatives⁵⁸ were interviewed, including government agencies (4), quasi-governmental agencies (2), international non-governmental organizations (INGOs) (4), United Nations (1), networks or mass organizations (1), local non-governmental organizations (LNGOs) (3) and PLHIV self-help groups (4). The survey was conducted in March 2006 in the two major economic centers of Vietnam - Hanoi and Ho Chi Minh City. The respondents had varied experiences in dealing with different HIV issues in Vietnam, working from community to policy levels. Respondents ranged in age from 20 to 55, and half of the respondents had participated in some way in the national review process.

For respondents who did not participate in the review process, representatives from LNGOs, CBOs, and especially self-help groups of PLHIV were selected to ensure a balance of vulnerable groups' representation.

Results

The survey revealed that the national review process was conducted over a very short time period – only three months for the entire process. The lack of time, the lack of understanding of the role of CSOs in HIV programming, and the lack of experience in involving CSOs in the national review process were the major hurdles to meaningful civil society participation.

The Vietnamese government had not adequately planned for civil society participation, and therefore information about the national review was not officially shared with civil society. Only some networks representing CSOs were invited to the final consultation meeting, at which the completed draft of

55 Vietnam Administration of AIDS Control, Ministry of Health, 2006.

56 National Strategy for HIV/AIDS Prevention and Control to 2010 with a Vision till 2020, 2004.

57 Prevalence rate is more than 1% of population.

58 Including organizations working with PLHIV, MSM, IDU, mobile populations, youth and women.

the country report was shared. Involvement of civil society groups such as LNGOs, community-based organizations (CBOs), PLHIV self-help groups, and faith-based organizations (FBOs) was largely ignored during the review process. However, the government expressed willingness for civil society to play a more valuable role in the process. In turn, civil society groups were eager to provide the necessary support.

While government and quasi-government participants expressed satisfaction with the UNGASS review process in Vietnam, civil society respondents surveyed expressed disappointment about their lack of participation. CSOs argued that they could make a significant contribution to the review process and country report if given the opportunity. Although their participation was minimal, all respondents expressed their commitment to improving the process for the next round.

The Vietnam Administration for AIDS Control (VAAC), the coordinating body of the review, was open to a more inclusive process and intends to provide a greater opportunity for the participation of CSOs in the next national review. UNAIDS and INGOs suggested they could assist in facilitating this involvement. The assessment also revealed that while CSOs, in general, have a sound knowledge of the GIPA Principle, their knowledge of UNGASS is limited.

OVERVIEW OF THE PROCESS IN VIETNAM

UNDP sent an official letter to ask for the UNGASS report sometime between September and October 2005. At the same time, the UNAIDS field office in Vietnam sent a letter to remind the Ministry of Health/VAAC about the preparation for the report, dated end October 2005. The Ministry of Health subsequently issued a decision to establish a task force for the UNGASS report, consisting of approximately 10 members.

The task force met and discussed a plan for the report's preparation and the designation of duties for each member, most of whom mainly came from the Ministry of Health and other relevant agencies. Each member was responsible for a part of the report including data collection, analysis, and writing. UNAIDS provided limited technical support for the process, chiefly through sharing guidelines for report writing and reminders about deadlines. UNAIDS also financed some VAAC staff to attend training courses on UNGASS review in Thailand before UNGASS 2006. Upon completion of the first draft, the VAAC organized a consultation meeting

at the end of December 2006. The draft report was shared via e-mail to all potential participants three days before the meeting. Participants were representatives of active international agencies in HIV (UN agencies, INGOs, and donors), and key national stakeholders (members of the National AIDS Committee). LNGOs and vulnerable groups were not invited to participate.

Although CSOs were not involved during the preparation process, some networks were invited to the final consultation meeting, including the Vietnam Red Cross Association, Women's Union, Confederation of Labor Unions, Youth Union, Farmer Association and Fatherland Front.

The draft report was clearly presented at the consultative meeting. VAAC created an open atmosphere for comments and discussion. Although there was inadequate time for full discussion and feedback, the meeting did result in some changes to the final report, especially with regard to comments from civil society participants. VAAC was receptive to feedback from other stakeholders, some comments being accepted and reflected in the final report. It was remarked that it would have been better if participants had had more time to review the draft report before the meeting. Although there was a lack of representation of LNGOs and vulnerable groups, VAAC did manage to engage representatives from networks or mass organizations (as they are defined in Vietnam) who were members of the National AIDS Committee in the final consultation meeting.

COLLABORATION BETWEEN GOVERNMENT AND CIVIL SOCIETY

Many respondents did not know what UNGASS or the UNGASS review process was, but given the importance of the documents, they argued that it should be widely distributed and shared by the government. Some respondents had heard about UNGASS, but most of them had not had an opportunity to read the document, especially in their mother tongue. Some claimed that UNAIDS had translated UNGASS into Vietnamese in 2001, but only a limited number of people had received this version.

Few civil society respondents knew that Vietnam had prepared and submitted two UNGASS reports in 2003 and 2006. The UNGASS national review process for 2006 was mentioned occasionally in INGO Technical Working Group meetings and at other similar events. However, only those who often attended such meetings received information. This was regarded as an informal announcement about

the review process and most civil society respondents were not satisfied with this approach. Only one survey participant from a LNGO received an official announcement from the government bureau about the national review process, but it did not require any action or attention. Most participants agreed that information sharing had occurred, but remained superficial.

Only respondents from the VAAC and UNAIDS felt they had actively participated in the process. The civil society representatives claimed that they passively participated because they did not receive an invitation or request to take part in the national review process. All representatives of self-help groups, LNGOs, and relevant vulnerable groups (IDUs, MSMs, and mobile populations) were not informed or invited to participate in the process. As a result, the national review process in 2006 was regarded by many as the work of a small team rather than a collective effort.

Table 4 Vietnam – Civil society agency perception of the level of participation in preparing the progress report on UNGASS indicators

Perceived level of involvement	Number of respondents
Interactive involvement	1
Functional involvement	0
Consultative involvement	3
Passive involvement	9
Total	13 out of 17 interviewed

Interviews with CSOs revealed that there was no mechanism or platform through which they could express their opinions. Some survey participants claimed that the potential contribution from CSOs, particularly from LNGOs and the most vulnerable groups, was underestimated. The UNGASS 2006 national review was considered a missed opportunity, and some commented that the process was not as organized in terms of involving civil society as the last UNGASS review in 2003. Information from VAAC revealed that time con-

straints were the major reason for limiting their efforts in conducting systematic and widespread consultation. In addition, there was no clear definition of civil society and no guidance on how to involve them. VAAC did not receive any technical support for the identification and involvement of CSOs. This is an important issue to consider for managing future partnership processes with civil society.

According to Bach Tan Sinh,⁵⁹ civil society has an established history in Vietnam. The difference between civil society in the past and today lies in the degree of participation, and the capacity to influence development. The definition of civil society should be interpreted within the context of the current Constitution of Vietnam,⁶⁰ which defines Vietnam as a state of, from and for the people. The principle «people know, people discuss, people execute, and people supervise», which can be heard repeatedly, reflects the wish of the government to encourage every social organization and citizen to participate in formulating, implementing, and monitoring policies.⁶¹

In the area of HIV prevention and control, civil society participation is essential and has been highlighted in different legal documents⁶² issued by the Communist Party and the government of Vietnam. The recently approved National AIDS Strategy⁶³ emphasizes that “the Central Committee of Vietnam Fatherland Front and its member organizations shall further mobilize the participation of the entire population in HIV/AIDS prevention and control ...To bring into full play the role and initiative of the Vietnam Fatherland front and mass organizations in mobilizing the people to actively participate in HIV/AIDS prevention and control.”

It is worth noting that CSOs such as the Women’s Union, Youth Union, Fatherland Front, Confederation of Labor Unions, Farmer’s Union, and the Red Cross Association are all active members of the National AIDS Committee and have been playing an important role in HIV prevention and control in Vietnam. Using CARE Vietnam’s classification of civil society, active CSOs can be grouped into three categories as follows:

59 Bach Tan Sinh, *Civil Society and NGOs in Vietnam: Some Initial Thoughts on Developments and Obstacles*, paper presented at the Meeting with the Delegation of the Swedish Parliamentary Commission on Swedish Policy for Global Development to Vietnam, at Horizon Hotel, 2 March 2001.

60 Socialist Republic of Vietnam, 1992, the Constitution of the Socialist Republic of Vietnam, Article 2, Chapter 1.

61 Using the criteria of being autonomous, having voluntary membership and representing the individual’s interest for the consideration of the government, CARE International in Vietnam has categorized CSOs in Vietnam into the following major groups: Traditional mass organizations; Professional associations; Professional centers; Community-based organizations. These definitions are important, especially since most methodologies and frameworks assume that civil society is defined universally.

62 The Ordinance on the Prevention and Control of HIV/AIDS, May 1995; The Directive of the Prime Minister on Strengthening HIV/AIDS Prevention and Control, February 2003; and the Directive of the Party Central Committee’s Secretariat, November 2005.

63 The National Strategy on HIV/AIDS Prevention and Control in Vietnam till 2010 with a Vision to 2020, pp. 146-149.

- **Traditional mass organizations (*Doan the*)**

Women's Union, Youth Union, Farmers' Union, the Vietnam Union of Science and Technology Associations (VUSTA), the Confederation of Labor Unions, Vietnam Veteran's Union, Red Cross Association, and the Vietnam Fatherland Front.

- **Professional centers** – Local NGOs, often registered with the Vietnam Union of Science and Technology Associations (VUSTA) or other umbrella associations.

- **Community-based organizations** – PLHIV self-help groups; other marginalized groups such as IDUs, sex workers and orphans; and charities or funds, including FBOs.

Different perspectives on civil society participation were described. Some argued that CSOs would not be interested in something that was not particularly relevant to their daily activities and did not directly benefit their programs. However, CSO representatives showed that they were very interested in the national review processes, but there was limited opportunity for their involvement.

Most respondents did not know how data had been collected for the national review process because they did not receive a request for data submission or participate in data collection. Most participants claimed the process was not transparent. The VAAC revealed that the report was written by many experts, each responsible for one part of the report. VAAC had assumed that the designated writing expert would contact relevant agencies to collect data. However, it is likely that most of the data was collected by desk review. Some participants expressed real concern about the limited time allocated for the whole process. Data collection requires intensive work and many independent surveys, making it difficult to systematically collect primary data within a short time frame.

During the national review process, technical support was provided by UNAIDS to the Vietnamese government, represented by VAAC. Two UNAIDS consultants worked closely with VAAC, mostly focusing on planning and clarifying the indicators used in the report. UNAIDS also provided financial support for writing the report and organizing the consultation.

Interviews with the VAAC showed that more technical support, including staff training, was needed. VAAC did not have sufficient human resources to systematically involve CSOs in the review process.

Other stakeholders, including UN agencies, INGOs, key sector ministries, LNGOs, and CBOs did not receive or provide any technical support, or receive an invitation or guidance on how to take part in the review process.

With the exception of the UNAIDS representative, no one was aware that there was a parallel process for civil society to submit information directly to the UNAIDS headquarters for UNGASS. Respondents said that they had not heard anything about it and had never contributed or submitted a parallel report. While the VAAC and UNAIDS were satisfied with the national review process, including the sharing of information on the review, data collection, participation, consultation procedures, and technical assistance, CSOs and other participants showed their disappointment. The most frequent response was dissatisfied. One major reason for this low rating was that respondents were only involved in the final consultation rather than in the whole process.

Most survey participants had limited opportunity and time to contribute. Those invited to participate had only three days to read and comment on a 67-page document. Some of them felt irritated by this and subsequently did not respond or attend the consultation. Participants from LNGOs and CBOs were the most disappointed because they were largely marginalized from the process. The lack of information sharing and interaction was mentioned by most participants.

UNAIDS and VAAC were overall very happy with the results of the UNGASS country report 2006. Although the report was prepared in a short time, it was considered by UNAIDS to be of high quality and one of the best country reports.

Other issues

UNDERSTANDING AND APPLICATION OF UNGASS, GIPA, AND THE CODE OF GOOD PRACTICE

In general, understanding of UNGASS and the DoC was limited, with the exception of some respondents from UNAIDS, INGOs, and VAAC. About half of those surveyed said that it is an international commitment for HIV prevention and control that focuses on prevention of HIV and the mobilization of resources. Most of the respondents have a sound knowledge and understanding of the GIPA Principle, with examples of how they may be operationalized. The common understanding of GIPA is that it aims

to promote the participation of PLHIV, placing them at the center for their own responses.

While UNGASS had been mainly used by VAAC and UNAIDS in programming and policy work, the GIPA Principle was used by all respondents in their daily work, especially in program design and implementation. When asked about the Code of Good Practice, only a few survey participants had heard of it, with no one having actually seen it. Although participants claimed that these documents were useful, there were no education activities provided on how to utilize UNGASS and the Code of Good Practice.

Conclusions and recommendations

Although the participation of CSOs in the national review process for UNGASS 2006 was low and passive, there is a commitment from all participants that it will be improved before the next round. Most CSOs did not realize there was a national review process which followed up the DoC from UNGASS. CSOs were not informed or consulted during the national review process. Only some representatives of mass organizations participated in the final consultation meeting. There was a final consultation meeting on the country report; however contributions from participants, including some representatives of CSOs, was limited due to time constraints at the meeting and the lack of time allowed for reading before the meeting.

Representatives of LNGOs, PLHIV groups and from other vulnerable groups such as mobile populations, IDUs, and sex workers were not informed or invited to participate in the process. They also were not invited to attend the final consultation meeting. The lack of technical support for VAAC and also for civil society contribution, limited the role and participation of CSOs in the process. VAAC should further examine means of involving civil society, and seek to obtain a greater understanding of the importance of their participation. While CSOs did have a sound knowledge of the GIPA Principle, the same is not true of UNGASS and, in particular, the Code of Good Practice.

The survey revealed that all participants were interested in increasing civil society participation in the forthcoming national review. The VAAC was open-minded about the issue and committed to improving the participation of CSOs in the next national review process. CSOs also showed interest in participating in the next review. INGOs and the

UN expressed a willingness to facilitate and support civil society involvement.

⌘ **Ensure ownership** – CSOs should realize their role and responsibilities within the national review process. Many did not believe that they had any responsibility for contributing to the monitoring and review of the implementation of the DoC. They considered this to be a role belonging entirely to the government. The government should have recognized the role of CSOs in UNGASS by ensuring the representation of all types of groups. Given that the number, importance, and variety of LNGOs and CBOs relevant to HIV is growing rapidly, their voices and experiences should be represented in future UNGASS reports.

⌘ **Integrate efforts with existing structures** – A mechanism and an enabling environment for the participation of CSOs should be created by concerned agencies. For instance, CSOs could participate, contribute, and access information on the national review process through HIV technical working group meetings and subgroup meetings, including those covering topics such as GIPA, care and treatment, sex work, men who have sex with men (MSM), harm reduction, and rehabilitation centers. This existing infrastructure can be used to involve interested CSOs and would enrich the process.

⌘ **Share information and raise awareness** – Information about the national review process should be widely disseminated so all relevant CSOs are given the opportunity to participate and contribute to the process. Representatives from LNGOs, CBOs, PLHIV and other marginalized groups, and FBOs should all be able to participate in the review process. Relevant agencies such as the Vietnam Union of Science and Technology Associations (VUSTA), which is the primary umbrella of LNGOS, should also be invited to participate. In order to provide a significant contribution to UNGASS, CSOs must gain a better understanding of UNGASS and the commitments that the Vietnamese government has pledged to meet. Additional communication and education activities to raise awareness about UNGASS with relevant agencies, including CSOs, should be provided.

⌘ **Provide technical support and institutional strengthening** – UNAIDS and INGOs should extend their support by providing technical support to both the Vietnamese government and CSOs in

areas such as partnership building. INGOs could play a role in facilitating the process and providing support for civil society to make a more meaningful contribution in the national review. This is particularly the case for marginalized groups and LNGOs who may need strengthened capacity in order to participate.

⌘ **Plan more effectively** – The lack of time for the review process and a lack of understanding about CSOs involved in HIV programming were given as the main reasons for not actively involving CSOs in the review process. INGO participants were optimistic about future reports and thought the process quite new, leaving room for improvement. More time for the national review

should be allocated to the government, as it takes time to prepare administration procedures, to collect and analyze data, and to prepare the report. More time should also be allocated in the future to ensure that civil society is represented in the process and the report.

A mapping exercise or study on the current role and contribution of civil society in HIV/AIDS programming should be conducted so that the government has a better understanding of what and how CSOs can contribute to the national review process. The results should be widely disseminated so that government and civil society agents understand their role and importance as concerns the AIDS response in Vietnam. ■

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Annex 1: CSO and Government Assessment Questionnaires

Survey of Civil Society Participation In Country-Level UNGASS 2006 Processes

INSTRUCTIONS⁶⁴ This climate survey is a questionnaire designed by CARE International to measure the participation of civil society related to the UNGASS national review process. The survey aims to identify the perceptions, attitudes, and opinions of the civil society and government. The survey is anonymous and participants are expected to answer the survey questions with objectivity and candor. No individual responses will be identified. Alternatively, trends will be identified, measured, and reported. All participants are assured that their responses will remain absolutely confidential and will be the sole ownership of CARE International.

Background variables. Some demographic information is needed to analyze the results of the survey and to develop plans on how to improve the UNGASS national review process. Background variables include the type of organization you work for, your gender, age group, and type of work managed by your organization.

Answers. In some cases, you might hesitate to answer a question because you have an impression and an opinion but no first-hand knowledge.

It turns out that what you think and how you feel is as important as what you know for sure in this type of survey. But, if you read a question and have neither first-hand knowledge nor any opinion, you are requested to leave it blank.

Your comments. When you complete this survey, if you feel there is a subject that has been overlooked for assessing the climate for involving civil society in the UNGASS national review process, you may attach a sheet with your comments. Do not include comments of a personal or confidential nature that cannot be published with results of the report.

Instructions for filling out the survey. Use either a pencil or a pen. Questions are either answered as "yes" or "no", by providing comments, or by rating. The rating scale is as follows:

- If you are strongly unsatisfied with the statement, circle 0
- If you are unsatisfied with the statement, circle 1
- If you feel neutral, circle 2
- If you are satisfied with the statement, circle 3
- If you are strongly satisfied with the statement, circle 4

There is no right or wrong answer – what you think or feel is what is important for this survey!

64 Consultants can read these instructions to interviewees and translate the information and questions, if needed.

Date of Survey:

Name of Organization:

Type of Organization: (circle one)

- Community-based (CBO)
- Women’s PLHIV Network
- Women’s group (non-PLHIV)
- NGO Network
- Government
- Faith-based (FBO)
- Youth PLHIV network
- OVC Org
- INGO
- Quasi-Government
- PLHIV network
- Youth group (non-PLHIV)
- NGO
- Trade Union
- Other:

Gender (M/F): Age:

Choose the primary location(s) where your projects are implemented. (circle all that apply)

- Urban
- Cross-border
- Peri-Urban
- Refugee/IDP Camp
- Rural
- Other:

Please describe your services, programs, and sectors where you work (i.e. health, agriculture, education, etc.).

.....

.....

.....

Choose the type of populations served by your projects. (circle all that apply)

- OVC
- Women
- PLHIV
- Sex Workers
- Refugees/IDPs
- Youth
- Men
- IDUs
- Migrant Laborers/other Mobile Populations
- Other:
- Child-headed households
- Elderly
- MSMs

Please provide a list of the donors funding your programs (i.e. Government, Global Fund, PEPFAR, DFID, INGOs, FBOs, UNICEF, private, etc.).

Describe the donors who fund your program and levels of support.

.....

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.....

Interview Conducted by:

Governments (to be completed by government participants only)

General UNGASS Background

Circle One:

1	Are you familiar with the UNGASS and/or Declaration of Commitment (DoC)?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

1A. Please describe.

.....

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.....

Circle One:

2	Are you familiar with Greater Involvement of People Living with HIV/AIDS (GIPA) Principle?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

2A. Please describe what you understand about GIPA.

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.....

.....

Circle One:

3	Are you familiar with the Code of Good Practice for NGOs Responding to HIV/AIDS?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

3A. Please describe what you understand about the Code.

.....

.....

.....

Circle One:

4	Do you use the UNGASS commitments, GIPA and/or the Code of Good Practice to shape your HIV/AIDS programming?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

4A. Please describe how you apply them.

.....

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.....

Circle One:

5	Do you have a straightforward mechanism to provide information to other ministries and/or civil society on your national HIV/AIDS programs so they are reflected in the UNGASS national progress reports?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	---	------------------------------	-----------------------------

5A. Please describe how you do this, who is responsible, and how often information is provided.

.....

.....

.....

		Unsatisfied		Very satisfied		
		0	1	2	3	4
5B.	How did you feel about the process?					
5C.	Please describe why you have selected your rating.				

		Circle One:	
6	Did you provide information to civil society for how you planned to collect data the plans for the UNGASS national review process?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

6A. Please describe how this information was provided.

.....

		Unsatisfied		Very satisfied		
		0	1	2	3	4
6B.	How did you feel about the process?					
6C.	Please describe why you have selected your rating.				

		Circle One:	
7	Have you invited civil society to participate in gathering information for the UNGASS national review process?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

7A. Please describe how you invited them, and who was invited.

.....

		Unsatisfied		Very satisfied		
		0	1	2	3	4
7B.	How did you feel about the process?					
7C.	Please describe why you have selected your rating.				

7D. Please describe what difference, if any, civil society participation made.

.....

7E. Please describe how women living with HIV and AIDS were involved in gathering information for the national reports.⁶⁵

.....

⁶⁵ Please reference The International Community of Women Living with HIV/AIDS (ICW) - Positive women monitoring change, May 2005 for additional information.

7F. How were young people involved in gathering information for the national reports?

.....

7G. How were other vulnerable groups involved in gathering information for the national reports?

.....

7H. Choose the type of vulnerable groups involved. (circle all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> OVC | <input type="checkbox"/> Youth | <input type="checkbox"/> Child-headed households |
| <input type="checkbox"/> Women | <input type="checkbox"/> Men | <input type="checkbox"/> Elderly |
| <input type="checkbox"/> PLHIV | <input type="checkbox"/> IDUs | <input type="checkbox"/> MSMs |
| <input type="checkbox"/> Sex Workers | <input type="checkbox"/> Migrant Laborers/other Mobile Populations | |
| <input type="checkbox"/> Refugees/IDPs | <input type="checkbox"/> Other: | |

Circle One:

8	Did you organize a workshop/forum for civil society to openly present and discuss the findings of the national progress report before the report was submitted to UNAIDS?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	---	------------------------------	-----------------------------

8A. Please describe the process and who was invited.

.....

	Unsatisfied		Very satisfied		
	0	1	2	3	4

8B. How did you feel about the process?

8C. Please describe why you have selected your rating.

.....

8D. Please describe what difference, if any, civil society participation made.

.....

8E. Please describe how women living with HIV and AIDS were involved discussing the findings of the national progress report.

.....

8F. How were young people involved in discussing the findings of the national progress report?

.....

8G. How were other vulnerable groups (IDUs, MSMs, migrant laborers, IDPs, sex workers, refugees, etc.) involved in discussing the findings of the national progress report?

.....

8H. Choose the type of vulnerable groups involved. (circle all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> OVC | <input type="checkbox"/> Youth | <input type="checkbox"/> Child-headed households |
| <input type="checkbox"/> Women | <input type="checkbox"/> Men | <input type="checkbox"/> Elderly |
| <input type="checkbox"/> PLHIV | <input type="checkbox"/> IDUs | <input type="checkbox"/> MSMs |
| <input type="checkbox"/> Sex Workers | <input type="checkbox"/> Migrant Laborers/other Mobile Populations | |
| <input type="checkbox"/> Refugees/IDPs | <input type="checkbox"/> Other: | |

Circle One:

8I. Did the final report reflect the discussions at this event? Yes No

Circle One:

9 Did you ask civil society organizations to review and comment on the final national progress report before it was submitted to UNAIDS? Yes No

9A. Please describe how you managed the review process and who was invited to participate.

.....

Unsatisfied **Very satisfied**

9B. How did you feel about the process? 0 1 2 3 4

9C. Please describe why you have selected your rating.

.....

Circle One:

10 Was technical assistance provided on gathering, analyzing and reporting data for the national report, including focused support to people living with HIV and AIDS? Yes No

10A. Please describe how this was provided and who was selected to participate.

.....

Unsatisfied **Very satisfied**

10B. How did you feel about the process? 0 1 2 3 4

10C. Please describe why you have selected your rating.

.....

Circle One:

11	Are you aware that UNAIDS has a parallel process for civil society to submit information directly to UNAIDS headquarters for UNGASS reporting?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
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12	Was the national report widely disseminated to civil society or made public before it was submitted to UNAIDS?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
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12A. Please describe how.

.....

Circle One:

13	Were UNAIDS staff at country-level available to help facilitate input from civil society throughout the process?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
-----------	--	------------------------------	-----------------------------

13A. Please describe how.

.....

	Unsatisfied		Very satisfied		
	0	1	2	3	4
13B. How did you feel about the process?					

13C. Please describe why you have selected your rating.

.....

Circle One:

14	Have financial resources been dedicated to facilitate civil society participation, especially for building capacity to fulfill their engagement in decision-making, planning, and policy development according to UNGASS targets?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
-----------	---	------------------------------	-----------------------------

14A. Please describe.

.....

15 What capacity building or training is offered to government employees to enable them to engage at different levels with civil society, especially with people living with HIV and AIDS for monitoring and reporting on UNGASS commitments?

15A. Please describe.

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Recommendations for Improving Civil Society Participation

16 How can links between government and civil society be improved for UNGASS monitoring and reporting?

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17 What could you do to be better involved?

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.....
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18 Who else should be involved?

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Do you have any other comments, suggestions or observations?

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Thank you for taking the time to provide this important feedback. We will be happy to make available a copy of the final report upon completion of the surveys.

Civil Society Questions⁶⁶ (to be completed by civil society only)

General National UNGASS Issues

Circle One:

1	Are you familiar with the UNGASS or DoC?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

1A. Please describe.

.....

.....

Circle One:

2	Are you familiar with Greater Involvement of People Living with HIV/AIDS (GIPA) Principle?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

2A. Please describe what you understand about GIPA.

.....

.....

Circle One:

3	Are you familiar with the Code of Good Practice for NGOs Responding to HIV/AIDS?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

3A. Please describe what you understand about the Code.

.....

.....

Circle One:

4	Do you use the UNGASS commitments, GIPA and/or the Code of Good Practice to shape your HIV/AIDS programming?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

4A. Please describe how you apply them.

.....

.....

Circle One:

5	Do you receive information on the activities of government and others related to the UNGASS monitoring and review processes?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

5A. Please describe how you receive this information and frequency of updates.

.....

.....

	Unsatisfied	Very satisfied			
	0	1	2	3	4
5B. How did you feel about the process?	0	1	2	3	4

5C. Please describe why you have selected your rating.

.....

.....

66 Some questions have been adapted from Panos Global AIDS Program, UNGASS Methodology, internal working document, July 2005, Results of Panos GAP Meeting.

Circle One:

6	Does your government have a way for you to provide information on your own activities so they are reflected in the UNGASS national progress reports?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

6A. Please describe how you provide this information, and how often updates are provided.

	Unsatisfied		Very satisfied		
6B. How did you feel about the process?	0	1	2	3	4

6C. Please describe why you have selected your rating.

Circle One:

7	Has your government provided you with information for how they plan to collect information for the UNGASS national review process?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

7A. Please describe how this information was provided.

	Unsatisfied		Very satisfied		
7B. How did you feel about the process?	0	1	2	3	4

7C. Please describe why you have selected your rating.

Circle One:

8	Has your organization been invited to participate in the UNGASS national review process?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
----------	--	------------------------------	-----------------------------

8A. If yes, how did you contribute and what type of information was provided?

	Unsatisfied		Very satisfied		
8B. How did you feel about the process?	0	1	2	3	4

8C. Please describe why you have selected your rating.

9	Did your government organize a workshop/forum to openly present and discuss the findings of the national progress report before the report was submitted to UNAIDS?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
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9A. Please describe how.

.....

.....

	Unsatisfied		Very satisfied	
9B. How did you feel about the process?	0	1	2	3
	0	1	2	3

10	Were vulnerable communities and PLHIV organizations asked to participate?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
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10A. Please describe how they participated.

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.....

10B. Choose the type of vulnerable groups involved. (circle all that apply)

<input type="checkbox"/> OVC	<input type="checkbox"/> Youth	<input type="checkbox"/> Child-headed households
<input type="checkbox"/> Women	<input type="checkbox"/> Men	<input type="checkbox"/> Elderly
<input type="checkbox"/> PLHIV	<input type="checkbox"/> IDUs	<input type="checkbox"/> MSMs
<input type="checkbox"/> Sex Workers	<input type="checkbox"/> Migrant Laborers/other Mobile	<input type="checkbox"/> Populations
<input type="checkbox"/> Refugees/IDPs	<input type="checkbox"/> Other:	

	Circle One:	
10C. Did the final report reflect the discussions at this event?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

11	Was your organization asked to review and comment on the national progress report before it was finalized and submitted?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
-----------	--	------------------------------	-----------------------------

11A. Please describe how.

.....

.....

	Unsatisfied		Very satisfied	
11B. How did you feel about the process?	0	1	2	3
	0	1	2	3

12	Was technical assistance provided on gathering, analyzing and reporting data for the national report, including focused support to people living with HIV and AIDS?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
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12A. Please describe how this was provided and who was selected to participate.

.....

.....

	Unsatisfied		Very satisfied		
	0	1	2	3	4
12B. How did you feel about the process?					

Circle One:

13	Are you aware that UNAIDS has a parallel process for civil society to submit information directly to UNAIDS headquarters for UNGASS reporting?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
-----------	--	------------------------------	-----------------------------

Circle One:

14	Has your organization submitted reports as part of the civil society parallel process ('shadow' reports)?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
-----------	---	------------------------------	-----------------------------

15 Civil Society Self-Rating⁶⁷

How would you rate your overall involvement in the UNGASS national review process?

Please circle the one that best describes:

Passive	Consultative	Functional	Interactive
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The following description will assist with defining the level various levels of involvement.

Interactive Involvement - civil society and government participate in joint analysis and development of national HIV/AIDS programs, monitoring and reporting. There are systems and processes in place beyond the development of the UNGASS national reports, which facilitate government and civil society involvement. Civil society is involved at the early stages of documentation and reporting related to the UNGASS national reports.

Functional Involvement - civil society and government participate by forming groups to meet related to the development of the UNGASS national reports only. Such involvement does not tend to be at early stages of report development planning, but rather after major decisions have been made.

Consultative Involvement - civil society participates in the process by being consulted by government. Government defines the issues submitted in the UNGASS national reports, and may modify these reports in light of civil society responses.

Passive Involvement - civil society participates by being told what is going to happen or has already happened by the government. It is a unilateral announcement without listening to peoples' responses.

15A. Please describe why you have selected your rating.

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.....

67 Adapted from the Catholic Relief Services (CRS) Partnership Tool

Recommendations for Improving Civil Society Participation

16 How can links between government and civil society be improved for UNGASS monitoring and reporting?

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17 What could you do to be better involved?

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18 Who else should be involved?

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Do you have any other comments, suggestions or observations?

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Thank you for taking the time to provide this important feedback. We will be happy to make available a copy of the final report upon completion of the surveys.

Annex 2

List of Respondents by Country

Cambodia

CHAWALIT NATPRATAN

Family Health International (FHI)

CHIN MARADY

Cambodian Youth Development (CYD)

CHOU BUN ENG

Ministry of Woman Affairs

GARY JACQUES

Centre of Hope

HENG SOKRITHY

Cambodian People Living with HIV/AIDS Network (CPN+)

JOHN TUCKER

Maryknoll (Pediatric AIDS Programme)

LY SOPHAT

Mith Samlanh (Friend)

LYN MAYSON

Save the Children Australia

MAO KIMRUN

Man Health Committee (MHC)

MAO SOVADEI

Child Welfare Department

MAO TAN EANG

National Tuberculosis Control Project (CENAT)

MATHEW WARNER SMITH

UNAIDS

MEAN CHHIVUN

National Centre for HIV/AIDS, Dermatology and STDs (NCHADS)

NICOLET HUTTER

Department for International Development (DFID)

OUM SOPHEAP

Khmer HIV/AIDS NGOs Alliance (KHANA)

PEN SAROEUN

School Health Department,
Ministry of Education Youth and Sport (MoEYS)

PRY PHALLY PHUONG

WOMYN'S AGENDA FOR CHANGE

SENG SOPHEAP

HIV/AIDS Coordination Committee (HACC)

SOK PUN

CARE Cambodia

TEK RA**KEO CHEN**

Cambodian People Living with HIV/AIDS Network (CPN+)

TENG KUNTHY

National AIDS Authority (NAA)

Kenya

ALLAN RAGI

Kenya AIDS NGOs Consortium (KANCO)

ALLOYS S. S. ORAGO

Coordination and Support, National AIDS Control Council (NACC)

ANISIA KARANJA

Kenyan Network of Religious Leaders Living with AIDS (KENERELA)

ANNALISA TRAMA

UNAIDS

ASUNTA WAGURA

Kenya Network of Women with AIDS (KENWA)

CAVIN OTIENE

Kenya Catholic Secretariat

DANIEL MWAURA

Kenya, Swedish Workplace HIV/AIDS Program with NOPE at the time of the review

ELIZABETH NGUGI

Kenyatta University in Nairobi

ELSA OUKO

Kenya Network of Positive Teachers, KENEPOTE

ESTHER MUNYISIA

Monitoring and Evaluation Unit, National AIDS/STD, TB and Leprosy Control Program (NASCOP/NLTP), Ministry of Health

FRANCE NJANG'IRU

HIV/AIDS Private Sector Business Council

G.M. BALTAZAR

National National AIDS/STD, TB and Leprosy Control Program (NASCOP/NLTP), Ministry of Health

GEORGE WAINANA

Kenya HIV/AIDS Private Sector Business Council

IGNATIUS KIBE

Kenya Consortium for Fighting AIDS, TB and Malaria (KECOFATUMA)

INVIOLATA M. MWBWANI

National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK)

JOE MURIUKI

National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK)

LATIF SHABAN

Supreme Council of Kenyan Muslims (SUPKEM)

MESHACK H.O. NDOLO

Ministry of Planning and National Development

MIANO MUNENE

Kenya AIDS NGOs Consortium (KANCO)

NOAH M. O. SANGANYI

Office of the Vice President and Ministry of Home Affairs, Department of Children's Services

RUKIA AHMED

Representing positive Muslim women

URSULA SORE-BAHATI

Office of the President, National AIDS Control Council (NACC)

Malawi

AMON CHINYOPHIRO

National Smallholder Farmers Association of Malawi (NASFAM)

ANOCK KAPIRA

MANET

BRAXTON BANDA

Center for Youth Development and Social Empowerment (CYDSE)

DAVID CHITATE

UNAIDS

DAVID NYIRONGO

National Association of People Living with AIDS in Malawi (NAPHAM)

FRANCINA NYIRENDA

MANASO

GRACE MALINDI

Ministry of Agriculture

JOHN CHIPETA

National AIDS Commission

JOSOPHART KAMTENGENI

Mchenzi Community Based Care

KELVIN GUTA

Chiwamba Root and Tuber Farmers Cooperative Society

MAXWELL MPHOMO

Edzi Kumdzi Association of Malawi (EKAM)

Thailand

BOONSANONG TUNGYUDEE

Thai NGO Coalition on AIDS

CHAREOMCHAI PEUNBUAPUN

Thai PLHIV Network

KAMONSET KAINGKANREU

Fasiroong Foundation (Rainbow group)

KANYALAK TIRACHINDADepartment of Social Welfare,
Ministry of Social Development
and Human Security**NAREELAK KULLERK**Bureau of Health Promotion,
Department of Health, Ministry of Public Health**PATRICK BRENNY**

UNAIDS

SERI JINTAKANON

Thai Drug Users Network

SOMCHAI SRIPLEINCHAN

Family Health International (FHI)

SUPAPORN TINWATANAKUL

Payao Development Foundation

SURACHAI PANAKITSUWAN

Thai Business Coalition on AIDS

SURASAK THANISAWANYANGKONBureau of AIDS, TB and STIs,
Department of Disease Control,
Ministry of Public Health**SUTIDA KANGSANTIA**Center for AIDS Prevention
and Problem Alleviation Administration,
Department of Disease Control,
Ministry of Public Health**THITIMA CHAREAONSUK**

Ministry of Education

THONGPHIT PINYASINWAT

Raks Thai Foundation

YENCHIT SOMPAOW

Thai National AIDS Foundation

United Kingdom**ALLAN ANDERSON**

Positively Women

ANGELINA NAMIBA

Positively Women

AVIVA BRESKY

All-Party Parliamentary Group on AIDS

BERNARD FORBES

UK Coalition of People Living with HIV and AIDS

CARL BURNELL

Gay Men Fighting AIDS

CHRIS MORLEY

George House Trust

DAVID JOHNSON

Waverley Care

DELPHINE VALETTE

UK AIDS and Human Rights Project

JERRY ASHUK Department for International Development
(DFID)**KAY ORTON**

Department of Health

LISA POWER

Terrence Higgins Trust

NAOMI FOXWOODUK Consortium on AIDS
and International Development**RHON REYNOLDS**African HIV Policy Network,
and UK Consortium
on AIDS and International Development**ROY KILPATRICK**

HIV Scotland

SALLY JOSSUK Consortium on AIDS
and International Development**YUSEF AZAD**

National AIDS Trust

Vietnam**BARBARA BALE**

CARE International in Vietnam

DAO MAI HOA

COHED (LNGO)

DAVID STEPHEN

Policy Project

DO TAT BUU

MSM group in HCMC

DO THI NHU TAM

Mobility Research and Support Center
(LNGO on mobile populations)

DO TRUONG THUY

Bright Future Network

DOMINIQUE RICARD

World Health Organization (WHO)

KHUAT HAI OANH

Institute for Social Development
and Studies

LE THUY LAN THAO

HCMC AIDS Committee

NANCY FEE

UNAIDS

NGUYEN THANH QUANG

Vietnam Administration
for AIDS Prevention and Control

NGUYEN THI BINH

Vietnam Women Union

NGUYEN THI HUYEN

PLWHA Network in the south of Vietnam

NGUYEN THI MINH TAM

Vietnam Administration for AIDS
Prevention and Control

NGUYEN THI NGA

SHAPC (LNGO on IDUs and MSM)

NGUYEN THI PHUONG MAI

UNAIDS

NGUYEN VAN TRUNG

Hope Group

PHAM THI THU BA

Ministry of Education

TRAN TIEN DUC

Policy Project