Minimum Standards for Civil Society Participation in the Universal Access Initiative
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The Coalition of Asia Pacific Regional Networks On HIV/AIDS

(Seven Sisters)¹

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¹ The Coalition of Asia Pacific Regional Networks on HIV/AIDS (the Seven Sisters) is a broad-based alliance bringing together seven regional networks: the Asia Pacific Network of People Living with HIV/AIDS (APN+), AIDS Society of Asia Pacific (ASAP), Asian Harm Reduction Network (AHRN), Asia Pacific Network of Sex Workers (APNSW), Coordination of Action Research on AIDS and Mobility in Asia (CARAM-Asia), Asia-Pacific-Rainbow (APR) and the Asia Pacific Council of AIDS Service Organisations (APCASO)
The universal access initiative refers to the commitment by United Nations member states to scale up HIV prevention, treatment, care and support to reach all who need it by 2010. Universal access processes will be integrated into national responses to HIV and AIDS and monitored at the national, regional and international level. The involvement of civil society in all processes related to universal access is essential to its implementation and outcomes.

This document, developed with input from civil society participants and organisations from the Asia-Pacific region, proposes a process and framework to encourage minimum standards for civil society participation in universal access processes, in other words, that a minimum set of requirements, actions, conditions or adherence to principles for civil society participation in universal access will be met and agreed to by governments and civil society.

This document is to be used by both civil society representatives as a tool to assess and promote their greater involvement in national universal access processes, and by national government representatives as a guide for ensuring civil society participation in universal access will be met and agreed to by governments and civil society.

Preparation work is needed by both civil society and government for minimum standards, including building consensus among civil society organisations and agreeing on how to select high quality and appropriate representatives for decision-making bodies. This work is crucial since an important part of civil society involvement in universal access will be participation on decision-making bodies. Once this work has been done, it is proposed that a facilitated process be followed for civil society and government to assess if government is meeting a minimum standard for civil society participation in each aspect and stage of universal access processes.

Civil society participation is a process through which civil society influences and shares control over initiatives, decisions, and resources that affect the segment of society which they represent by being meaningfully involved in all phases of planning, dissemination, implementation, and monitoring and evaluation of policies and programs. Five levels of participation have been differentiated: non-participation, passive involvement, influence, partnership and self-mobilisation; and these levels have been assigned scores from 0 – 4.

To assess civil society participation, universal access processes have been divided into three aspects:

1. Establishment of Universal Access Processes / Target-Setting;
2. Implementation and Monitoring and Evaluation; and
3. Resources.

Each of these aspects will be evaluated in each of three stages:

1. Planning;
2. Decision-making; and
3. Representation.

Using the proposed matrix, indicators, and score sheet, civil society and government should assess the level of civil society participation in universal access processes and develop an action plan to improve participation if it is insufficient. If the government sector does not agree to collaborate, other stakeholders such as UNAIDS may be able to facilitate dialogue and negotiations. If this fails, civil society should undertake the scoring system independently.

In each of the three stages of each of the three identified aspects of Universal Access, the minimum standard for civil society participation is [2: influence]. This means that civil society has authentic involvement in some way that goes beyond information-sharing or token representation. For example:

- Civil society has opportunity for input through meetings and consultations for target-setting, implementation, monitoring and evaluation, and resource allocation for universal access.
- Civil society is involved and taken seriously in universal access planning.
- A memorandum of understanding exists that recognises a commitment by government to working with civil society.
- Civil society has influence on its representation on relevant universal access bodies.

However, this tool is not meant as a way for governments to reach a minimum standard of participation and not improve involvement of civil society; beyond influence, both parties should aim, where possible for, [3: participation] and [4: self-mobilisation], recognising that civil society participation must inform universal access processes in order to make them effective and responsive to local contexts.

2 Civil society refers to non-state entities. A fuller definition is on page 30. Some resources refer instead to the “community sector.”

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**Executive Summary**

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Structure

The main body of the document is divided into three parts. The first part describes preparation needed by civil society and the government sector in order to implement a system of minimum standards, and proposes a facilitated process for civil society and government to agree on what constitutes a minimum standard for participation in each aspect and stage of development.

The second part proposes a process using a matrix which includes a scoring system based on definitions of levels of participation and sets of indicators which are used to examine the different aspects and stages of universal access. An example is given of how to use the matrix, indicators and scoring system, along with a score sheet. An additional discussion follows on challenges of scoring.

In the third part, the document describes monitoring and evaluation models for assessing civil society participation, and examines next steps for how this proposal for minimum standards can be developed, used and disseminated.

For readers who are not familiar with the initiatives and principles which this document addresses, background information is provided in the appendices. These sections explain the genesis of this proposal; what universal access is, how the initiative was developed and relevant frameworks; and the necessity for civil society participation in responses to HIV, particularly at the national level, and the many challenges to that participation. Previous discussions of the concept of minimum standards as applied to civil society participation are reviewed. Following this is an overview of different models for civil society participation in national responses to HIV and AIDS.
PART 1: PREPARATION

1a. Minimum Standards for Civil Society Organisations

Before adopting minimum standards for civil society participation in universal access processes, preparation work is needed. Civil society will need to define itself, and agree on how it will work together. In countries with established community sectors with recognised national AIDS umbrella organisations, this may not be necessary. However, it could serve as a useful reaffirmation or evaluation of who of civil society must be involved.

It will also be necessary, if advocating for government to adopt minimum standards, that civil society also adhere to minimum standards for how it operates and is governed. These can be used by civil society to be held accountable to its members as well as to its government. As suggested at the Asia Pacific Regional Civil Society Forum on “Moving Towards Universal Access” (August 2006, Bangkok), Civil Society Organisations and NGOs should adhere to the principles articulated in “The Code of Good Practice for NGOs Responding to HIV/AIDS”\(^3\). The Code of Good Practice identifies guiding principles, organisational principles, and programming principles which have been signed by over 160 international and national NGOs. An agreement could be made on principles relevant to universal access which could be adopted as minimum standards. This could be done by civil society independently, or as a collaboration with national governments, for example:

- We have transparent governance and are accountable to our communities/constituencies
- We share information and communicate with our members and constituents about our work, and the key activities that we are involved in (such as universal access processes)
- We manage financial resources in an efficient, transparent and accountable manner
- We advocate for the meaningful involvement of PLHIV and affected communities in all aspects of the HIV/AIDS response

Another relevant source of guidelines for civil society participation was developed by GNP+ and Policy Project in consultation with over 400 PLHIV and aimed at PLHIV members of Global Fund CCMs.\(^4\) Included are practical recommendations on ensuring diverse representation, being well-prepared for meetings, induction for representatives, appointing alternative representatives, and desirable personal qualities such as: good interpersonal and public relations, preparation, and the willingness to “ask probing questions and demand honest answers.”

The process of selecting civil society representatives will be of critical importance to civil society participation in universal access processes. By leading and facilitating the process, the community sector can:

- Display good practice in terms of running a process that is open and transparent, and in communicating the results of that process
- Provide a model to ensure that governments do not hand-pick community representatives
- Contribute to greater consensus among and collaboration between civil society organisations
- Build the capacity and skills of those involved in the process.

ICASO, AfriCASO and the International HIV/AIDS Alliance have produced a comprehensive set of guidelines, “Coordinating with Communities”\(^5\), for involving the community sector in the “Three Ones”\(^6\) which is highly relevant to the issue of civil society participation in universal access. As part of this document, they have produced a set of eleven Action Cards to provide guidance for a range of activities to improve community sector participation. We recommend that a number of these Action Cards be used in particular in relation to minimum standards.

The first Action Card describes a process for the community sector to define itself if it has not done so already. It recommends that this process be facilitated by respected and recognised leaders, organisations, or a coordination group within the community sector, and

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3 International Federation of Red Cross, 2005.
5 ICASO, AfriCasO and the Alliance, “Coordinating with Communities”, 2007.
6 For a description of the Three Ones, see Appendix 1: Background: Processes and Participation.
where none exists, a working group convened of community sector stakeholders. Through this process, the sector can define itself according to the characteristics related to the epidemic and the conditions that make certain communities more affected by HIV and AIDS. A further development would be for the sector to support and improve its consensus building, for example, in agreeing on the procedures and processes by which it reaches consensus.

The next relevant action card is for a selection process for the community sector/civil society. The first part of the selection process is to identify roles, responsibilities and selection criteria for civil society representatives. ICASO et al propose the following steps:

1. The community sector facilitates a process to identify the appropriate type and number of community sector representatives on relevant bodies, reflecting a diversity of communities and groups.
2. A coordinating group develops terms of reference for the representatives, both for their key roles and responsibilities as well as the experience, qualities and skills required of them.
3. The community sector documents the terms of reference into a job description and selection criteria which is made widely available.

The second part of the selection process is to select community sector representatives based on the following principles:

- Independent of other sectors and the national coordinating body on which the representatives will serve.
- Focused on selecting representatives who can fulfil the:
  - Terms of reference for the members of the coordinating body
  - Roles and responsibilities and selection criteria agreed by the community sector for its representatives
- Focused on ensuring a diversity of representatives (e.g., by using a rotational system).
- Fair, democratic and based on building consensus.

- All-inclusive, involving as many community sector constituents as possible.
- Safe (e.g., people living with HIV must be able to maintain their confidentiality if they wish to).
- Transparent (the processes and results must be accessible to all).
- Thorough (e.g., includes a plan in the event that two candidates receive an equal number of votes).
- Aware of power dynamics (e.g., ensuring that the largest NGO is not automatically selected just because it has the highest profile).
- Focused on a model of representation that suits the culture and democratic norms of the country.
- Focused on a model that ensures that representatives are never ‘on their own’ and that involves selecting alternates or a team of representatives, rather than just individuals.

Below we propose ICASO’s Action Card on selecting civil society representatives as a prerequisite to civil society participation in universal access processes.

1b. Civil Society Participation: Representation

Objective: Civil society is represented by legitimate representatives chosen through a democratic and transparent process

The selection of civil society representatives for universal access by civil society itself is an integral part of universal access processes. Rather than being a part of the scoring system to be evaluated by civil society and the government sector, it is a pre-requisite stage. Civil society will need to appoint a coordinating body and secretariat to organise the selection process and develop and agree on principles and working procedures, for example, how affected communities will be represented.

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7 Ibid 34, adopted from “Action Card 2.”
8 Ibid 34, adopted from “Action Card 3.”
9 Adapted from “Coordinating with Communities”, 2007. Part B. Section 1.2.2 Selecting Representatives.
Some communities of people engage in behaviours such as unprotected sex or exchange of contaminated needles that put them at higher risk of becoming infected with HIV. These communities include men who have sex with men, people who use injection drugs, and sex workers.

In many areas of the world, the HIV epidemic has had a serious effect on human development, and has left people who are already vulnerable, such as women and girls, young people and children, refugees and internally displaced persons, and migrants, at higher risk of acquiring HIV.10

Affected communities will be reflected in national data on HIV infections. Representation on committees should reflect epidemiology. For example, an epidemic primarily in drug users should see strong drug user representation on committees. The same principle could be applied to youth or women representation.

Unlike the indicators which will be used later in this document, this section instead lists pre-requisite steps necessary to the selection process.

Pre-requisite steps:

1. The coordinating body and members promote procedures to select representatives who can provide a comprehensive range of high quality input and expertise

2. The coordinating body and members promote procedures to select representatives that represent a diversity of the national HIV response (taking into account such factors as affected communities, gender, geography and types of NGOs/CBOs (i.e. large vs. small, constituencies, faith-based)

3. The secretariat disseminates a formal invitation to the civil society to self-select an agreed number of representatives

4. Civil society identifies and agrees on the selection criteria and process for its representatives

5. Civil society selects the agreed number of representatives

6. After the selection process, the representatives provide information to other stakeholders about who they are, who they represent and how they were selected.

7. All stakeholders acknowledge each group’s selected representatives and treat them with respect and equality. This can involve public announcements of representatives.

8. The community sector agrees on a set of requirements for how representatives are accountable to their constituencies, which could include presentations or written reports.

Civil society may also want to develop a system for monitoring whether these steps have been enacted and evaluating how well they have been implemented.

1c. A Working Agreement between Government and Civil Society

Preparatory work by government will also be necessary, and in order to implement minimum standards for civil society participation, some kind of working agreement between government and civil society will be needed.11

The working agreement between civil society and government would aim to reach consensus on key points such as:

1. Whether the indicators are appropriate and applicable to the national context

2. What constitutes a minimum standard for this area

3. How to use the results of the evaluation.

Ideally, facilitators agreed upon by both parties are used by government and civil society to each do individual assessments on the indicators, and then come together to compare and discuss the results. During such a meeting, parties would compare scores and negotiate an agreed final score. If there is a need for improvement, a set of actions should be formulated and agreed upon.


11 However, as a precursor to this, it is likely necessary to build collaboration and support between both stakeholders. Ways to do this can be found in other resources. For example, Action Card #10 in ICASO et al’s “Coordinating with Communities”, 2007 describes practical steps such as “clarifying what each means by partnership”, “building mutual understanding” and “developing and agreeing on working principles.”
1d. Involvement of Other Stakeholders

In all parts of this process—preparatory work, scoring, monitoring and evaluation and follow-up action plans—the involvement of other stakeholders, such as UNAIDS and other multilateral agencies and donors, may be useful. They can help facilitate the relationship between civil society and government, particularly in being able to act as an impartial, objective observer to the process. In contexts where civil society organisations or representatives are inexperienced or lack capacity, other stakeholders can provide mentoring, resources, and other forms of support. These partners may also be given tasks to assist with the process which could be specific such as facilitation or note-taking, or general, such as helping both parties to understand the latest developments and progress in universal access at the regional and international levels.

1e. Summary of Preparatory Work

- Civil society defines itself, agrees on how it will work together, and chooses its representatives.
- Civil society requests a meeting with government to discuss minimum standards for civil society participation in universal access processes.
- The involvement of other stakeholders, such as UNAIDS or donors, may be useful to facilitate the relationship between government and civil society.
- Civil society and government agree through a facilitated process how they will work together, review the indicators and choose which ones will be used, and review the scoring framework and how it will be used. They will agree or affirm for each area what constitutes a minimum standard.
- The process will also define how the scoring process will take place, and how civil society and government will follow up on results.
- If the government sector is not conducive to this agreement, civil society will go through the process independently, and a priority for civil society advocacy will then become how to work towards a minimum standard of collaboration with the government.
PART 2: SCORING AND INDICATORS

2a. Methodology

Following is a description of procedures to assess the level of participation of civil society in universal access processes. The matrix below which shows universal access processes, stages in these processes, and evaluation indicators. We have divided universal access into three main processes: establishment of UA processes, including target-setting; implementation, and providing resources. Later, the matrix will be adapted into a score sheet which will include a space for agreeing on next actions.

<table>
<thead>
<tr>
<th>Establishment of universal access processes / target-setting</th>
<th>Implementing, Monitoring and Evaluating</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decision-making and Agreements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Representation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**The establishment of universal access processes** will include target-setting (setting interim targets for 2008 and full targets for 2010) and the development of national plans and strategies. **Implementation** will include management of projects and activities to reach set targets, resetting of targets if necessary, and monitoring and evaluation of progress on reaching targets. **Resourcing** universal access will include decision-making on national budgets, and how consultations and decision-making bodies are funded.12

We have divided the three processes into three stages: planning, decision-making, and representation. Indicators have been developed for each aspect and stage for measuring and communicating the impact or result of methods to involve civil society in national universal access processes and whether an agreed on minimum standards has been obtained. These indicators will be used to assign a score based on a framework, presented below, based on different levels of civil society participation in national processes.

We propose the following overarching goals to maximize civil society participation in universal access processes.

1. **Civil society is represented by legitimate representatives chosen through a democratic and transparent process. (Representation)**
2. **Civil society participates in transparent and open consultation and is a part of any decision-making bodies or processes related to assessing, planning, implementing, monitoring and evaluating universal access processes. (Participation)**
3. **Support for civil society participation in universal access processes is documented and agreed on and resources at the national level are identified, mobilised and used to support civil society participation in universal access processes. (Support)**

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Text Box: The Use of Indicators.
Indicators are ‘signals’ that show whether program objectives and activities are realistic and feasible, as well as to monitor progress towards objectives. For the minimum standards project, indicators will provide a way of measuring and communicating the impact or result of methods to involve civil society, and whether an agreed on minimum standards has been obtained.

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12 Civil society should also bear responsibility for raising funds for its involvement in UA processes. A strategy is provided in “Coordinating with Communities” (ibid 17), Part C: Action Card 6: Raising Funds for Community Sector Involvement” p. 17-8
In order to advocate for a sufficient level of civil society participation in universal access processes, it is useful to define participation. For the purposes of this proposal, we propose defining civil society participation in national processes into five levels in terms of the relationship between civil society and government. These five levels will be used as the scoring framework to evaluate whether minimum standards are being achieved.

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Non-participation</td>
</tr>
<tr>
<td></td>
<td>a) Lack of information sharing;</td>
</tr>
<tr>
<td></td>
<td>b) Government agencies are in full control and make no effort to change the situation;</td>
</tr>
<tr>
<td></td>
<td>c) Government agencies’ agenda takes precedence over that of the civil society;</td>
</tr>
<tr>
<td></td>
<td>d) Government agencies define and implement policy without any civil society input;</td>
</tr>
<tr>
<td></td>
<td>e) No strategic plan to involve civil society;</td>
</tr>
<tr>
<td></td>
<td>f) Various nuances of this level are:</td>
</tr>
<tr>
<td></td>
<td>I. Manipulation: civil society may be engaged only for the benefit of the government agencies and may not receive full information on the implications, or may be misled, misinformed or even bribed and coerced;</td>
</tr>
<tr>
<td></td>
<td>II. Decoration: civil society may be called in just to embellish government agencies’ actions, for instance through performances, song, dance and other entertaining activities without relevance to the content and substance of the event.</td>
</tr>
<tr>
<td>1</td>
<td>Passive involvement</td>
</tr>
<tr>
<td></td>
<td>a) Some level of information sharing; but it may be only in one direction, from government to civil society;</td>
</tr>
<tr>
<td></td>
<td>b) Minimum effort is made to inform and involve civil society;</td>
</tr>
<tr>
<td></td>
<td>c) Civil society is listened to only at a superficial level;</td>
</tr>
<tr>
<td></td>
<td>d) Tokenism: civil society may be given a voice merely to appear to be friendly to civil society.</td>
</tr>
<tr>
<td>2</td>
<td>Influence</td>
</tr>
<tr>
<td></td>
<td>a) Information sharing is a two-way flow;</td>
</tr>
<tr>
<td></td>
<td>b) Civil society is consulted on a one-off or regular basis. They are involved, and taken seriously;</td>
</tr>
<tr>
<td></td>
<td>c) Civil society has a sense of influence which encourages ownership;</td>
</tr>
<tr>
<td></td>
<td>d) Sub-stages of this level are:</td>
</tr>
<tr>
<td></td>
<td>I. Assigned but informed: government agencies take the initiative to inform civil society. Only after the civil society understands the goals of a program or policy and their own role does civil society decide whether to become involved;</td>
</tr>
<tr>
<td></td>
<td>II. Consulted and informed: civil society is extensively consulted on projects, programmes and policies designed and run by Government agencies.</td>
</tr>
</tbody>
</table>

13 This section was adapted from Gerard de Kort’s work integrating various theories on youth participation by Roger A. Hart, Roger Holdsworth, and Gill Westhorp, as well as the World Bank’s levels of community participation (The World Bank Participation Source Book, 1996). It was also informed by the work of Dr. Walter Eberlei, “Institutionalised Participation in Processes Beyond the PRSP” September 2001. For his analysis of Poverty Reduction Strategies in Africa, he reviewed relevant literature and distinguished between four and six degrees of civil society participation.
Partnership

a) Collaboration: civil society has increasing control over decision-making and implementation of processes and projects;
b) Government agencies make a concerted and structured effort for genuine civil society participation;
c) Government agencies and civil society form a meaningful partnership with negotiation on and delegation of tasks;
d) Government agencies initiate shared decision-making with civil society.

Self-mobilisation

a) Empowerment: transfer of control over decisions and resources to civil society;
b) Civil society are empowered to take the lead on decisions and projects.
c) Civil society is in full control and may choose to seek Government agencies assistance, if necessary and desired;
d) Nuances of this stage are:
   I. Civil society-initiated and directed: civil society conceives, organises and directs project, programmes and policies themselves, without Government agencies’ interference (but with the support of the government);
   II. Civil society-initiated, shared decisions with Government agencies: civil society conceives, organises and directs project, programmes and policies but shares decision-making with Government.

Here are examples to illustrate each level of participation in relation to:

a. national decision-making processes on HIV, and
b. national monitoring and evaluation processes.

a. national decision-making processes on HIV

<table>
<thead>
<tr>
<th>Level of Participation</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Participation</td>
<td>Civil society organisations have no information or influence on national AIDS policy</td>
</tr>
<tr>
<td>Passive Involvement</td>
<td>National AIDS Councils distributes and shares information with civil society organisations</td>
</tr>
<tr>
<td>Influence</td>
<td>National AIDS Councils consults on a one-off or regular basis with civil society representatives</td>
</tr>
<tr>
<td>Partnership</td>
<td>Key decisions in processes or on projects require the participation of both national and civil society representatives; National AIDS Councils and Civil Society Organisations or Representatives collaborate on specific processes or projects</td>
</tr>
<tr>
<td>Self-mobilisation</td>
<td>Civil society representatives or organisations control parts of decision-making processes and are empowered to take the lead on certain decisions or projects</td>
</tr>
</tbody>
</table>
b. national monitoring and evaluation processes

An important part of the universal access process will be the monitoring and evaluation of whether countries are reaching their set targets.

<table>
<thead>
<tr>
<th>Participation in M&amp;E by Civil Society</th>
<th>Scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Participation</td>
<td>Monitoring and evaluation processes are carried out solely by government or government-appointed bodies.</td>
</tr>
<tr>
<td>Passive Involvement</td>
<td>Civil society organisations receive information about the national M&amp;E process from relevant bodies</td>
</tr>
<tr>
<td>Influence</td>
<td>The National AIDS Council organises a consultation with a range of civil society representatives to advise on how M&amp;E of universal access will be carried out</td>
</tr>
<tr>
<td>Partnership</td>
<td>Civil society is represented on relevant UA bodies and work together to make decisions on an action plan for how M&amp;E will be implemented and by whom.</td>
</tr>
<tr>
<td>Self-mobilisation</td>
<td>Civil society representatives are empowered with necessary financial and human resources (which could include training) to take a leading role in monitoring and evaluation.</td>
</tr>
</tbody>
</table>

These levels are translated into a scoring system from 0 to 4 points which is then applied to three universal access processes and their stages, as described above.

2c. Scoring Challenges

Considering the levels of participation defined above, what level of participation should constitute a minimum standard? Even though civil society development and capacity varies from country to country, we suggest the following regarding civil society participation:

- (0) non-participation is not acceptable
- (1) passive involvement is not acceptable.
- (2) influence is acceptable
- (3) partnership is desirable
- (4) self-mobilisation represents best-practice or an ideal

Therefore, we propose (2) influence as a minimum standard.
The scoring framework may be adapted to each aspect and/or stage of universal access processes. For example, as applied to aspects:

<table>
<thead>
<tr>
<th>Establishment/ Target-setting</th>
<th>Implementation / M&amp;E</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>(0) non-participation</td>
<td>(0) not involved in planning or target-setting</td>
<td>(0) no resources allocated, no involvement at all</td>
</tr>
<tr>
<td>(1) passive involvement</td>
<td>(1) civil society informed of target-setting</td>
<td>(1) civil society informed of implementation and M&amp;E</td>
</tr>
<tr>
<td>(2) influence</td>
<td>(2) civil society has opportunity for input through meetings/consultations</td>
<td>(2) civil society has opportunity for input through meetings/consultations</td>
</tr>
<tr>
<td>(3) partnership</td>
<td>(3) civil society involved in target-setting in partnership w/government</td>
<td>(3) civil society makes decisions in some areas in partnership w/government</td>
</tr>
<tr>
<td>(4) self-mobilisation</td>
<td>(4) civil society manages and controls appropriate parts of the target-setting process</td>
<td>(4) lead role for civil society in M&amp;E</td>
</tr>
</tbody>
</table>

The scoring framework can also be applied to each of the stages:

<table>
<thead>
<tr>
<th>Planning</th>
<th>Decision-making and Agreements</th>
<th>Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>(0) non-participation</td>
<td>(0) not involved in any way in planning or target-setting</td>
<td>(0) no agreements exist, no involvement at all</td>
</tr>
<tr>
<td>(1) passive involvement</td>
<td>(1) sharing of information with civil society but limited influence</td>
<td>(1) some references to civil society in relevant documents</td>
</tr>
<tr>
<td>(2) influence</td>
<td>(2) civil society involved and taken seriously in UA planning</td>
<td>(1) minimum effort to represent civil society</td>
</tr>
<tr>
<td>(3) partnership</td>
<td>(3) collaboration between civil society and government on all UA planning</td>
<td>(2) MOU but no minimum standards</td>
</tr>
<tr>
<td>(4) self-mobilisation</td>
<td>(4) civil society empowered to take lead role in planning</td>
<td>(3) agreement between civil society and gov’t on civil society representation</td>
</tr>
<tr>
<td></td>
<td>(4) agreements and minimum standards exist and are fully enforced</td>
<td>(4) civil society controls who and how many representatives on relevant UA bodies</td>
</tr>
</tbody>
</table>
There may be challenges due to the subjective nature of qualitative scores. These will depend on the viewpoint of the person or group assigning them. It will be a challenge to make sure that the score is as objective as possible, unbiased by political or personal motive, and based on a clear and transparent methodology. However, these scores are not meant to be scientific. The scores, indicators and the framework proposed seek to provide a practical tool for civil society participation: assessing, monitoring and evaluating civil society participation, and using the results to maintain or improve the quality of participation.

Another challenge is to consider who will control the scoring and reporting process. As proposed, the process should be a collaboration between civil society and government, with negotiation to ensure that both parties agree on the evaluation. If civil society undertakes this process independently, they would need to be clear how civil society is being defined, who are their representatives, who are their constituencies and whether they are collaborating with the full, rather than partial, range of affected communities. The findings may be accepted as more accurate if an impartial body can do the assessment, for example, a coalition of business groups, or a civil society body that is, by choice, staying outside of universal access processes.

2d. Instructions

- Indicators have been developed for each stage (planning, decision-making and agreements, and resources) and aspect (establishment, implementation/M&E, and resources) of universal access processes.
- Government and civil society are encouraged to adapt or add indicators where necessary.
- Each set of indicators is to be reviewed to assess overall progress in each area.
- Based on the indicators in each box, a score between 0 - 4 is awarded to each box in the score sheet below.
- It might be useful to calculate average scores per ‘aspect’ and/or ‘stage’, and finally a ‘total score’ be calculated which would be the average of all the others.\(^\text{14}\)
- For assessment purposes, an average of 2 or higher could be considered as ‘according to minimum standards’.
- Ideally, civil society and the government sector should participate in a dual process, each using the indicators separately to assess civil society participation in universal access through focus group discussions assisted by facilitators who are knowledgeable of the local context and familiar with the indicators and related scoring framework.
- Any differences in scoring should be discussed at a joint meeting after which a plan of action can be adopted to improve scores that may be perceived as too low.
- Such a process would take approximately one day.
- The first filled out score-sheet can be used as a base-line to evaluate progress.

\(^{14}\) However, it should be stressed that the main purpose of this exercise is not playing with numbers and mathematics but to place civil society participation firmly on the universal access agenda. Discussing and promoting this participation are the key ingredients of this process.
## 2e. Matrix: Milestones and Indicators for Civil Society Participation in UA Processes

### Matrix\(^{15}\)

<table>
<thead>
<tr>
<th>Establishment of universal access processes / target-setting</th>
<th>Implementing, Monitoring and Evaluating</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Planning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The content and purpose of the consultation was clear.</td>
<td>Civil society has had meaningful participation in setting interim targets for 2008 and full targets for 2010; Civil society is to participate in monitoring and evaluating progress achieved towards universal access targets either through i/ a collaborative process with the government; or ii/ A separately funded “shadow” or independent M&amp;E process (“watchdogging”).</td>
<td>Funds and resources are made available where needed to support a process to select civil society representatives.</td>
</tr>
<tr>
<td>The consultation was aimed at the target audience in objectives, content and accessibility; All communication was sufficiently complete and concise, and encouraged responses from interested parties; The timeframe for participation was long enough for consulted parties to be able to adequately prepare, consult with constituents and, if necessary, submit responses; The consultation was publicised as broadly as possible; The groups consulted were able to freely and openly express their views; If translation or interpretation was required by civil society participants to allow them to fully participate in the meeting, was provided by the meeting's convenors; Civil society representatives have been provided with all relevant information to inform the decision-making process (including draft plans, proposed targets, plans to measure progress etc); Civil society has seen, and formally agreed upon, all key decisions before they are made public; The report produced as an outcome of the consultation accurately reflected the discussions that took place, including debate or dissent; The report produced as an outcome of the consultation accurately reflected the discussions that took place, including debate or dissent.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

15 Many of these indicators were adapted from ICASO et al’s “Coordinating with Communities”.

<table>
<thead>
<tr>
<th>Establishment of universal access processes / target-setting</th>
<th>Implementing, Monitoring and Evaluating</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Decision-making and Agreements</strong></td>
<td>Government and civil society have agreed on and established procedures for ensuring civil society participation in the implementation of projects or initiatives aimed at achieving universal access targets; Civil society involved in written reports on monitoring and evaluation of progress on reaching universal access targets, civil society participation, and minimum standards implementation. Involvement could take the form of researching, writing and/or final approving.</td>
<td>Institutional development and capacity-building support is occurring (ongoing programs / workshops) in order to improve the capacity of civil society to represent their constituencies; Institutional development and capacity-building support is occurring (ongoing programs / workshops) in order to improve the capacity of civil society to collaborate with the government and its agencies in universal access processes; Institutional development and capacity-building support is occurring (ongoing or one-off training programs or workshops) in order to improve civil society capacity to strengthen their networks;</td>
</tr>
<tr>
<td><strong>Representation</strong></td>
<td>On decision-making bodies related to implementing and M&amp;E of universal access: a/ Not less than one third civil society participation b/ Number of seats or percentage of participation by affected communities (particularly marginalised groups) c/ Number of seats or percentage of participation by people living with HIV</td>
<td>On decision-making bodies related to allocating resources to universal access a/ Not less than one third civil society participation b/ Number of seats or percentage of participation by affected communities (particularly marginalised groups) c/ Number of seats or percentage of participation by people living with HIV</td>
</tr>
<tr>
<td>On decision-making bodies related to planning universal access: a/ Not less than one third civil society participation b/ Number of seats or percentage of participation by affected communities (particularly marginalised groups) c/ Number of seats or percentage of participation by people living with HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Existence of a strategic plan for achieving universal access that has included the participation of civil society in its development; Terms of reference that clearly define the role of civil society in universal access decision-making bodies or processes have been developed; Memorandum of Understanding or Commitment between government and civil society representatives for universal access collaboration has been agreed upon and signed; Where required, progress is occurring in improving civil society participation in decision-making bodies or processes; The national plan for HIV recognises the intrinsic role of civil society and commits to its active participation; Agreement is reached amongst all stakeholders on minimum standards for civil society participation in universal access processes;</td>
<td>Government and civil society have agreed on and established procedures for ensuring civil society participation in the implementation of projects or initiatives aimed at achieving universal access targets; Civil society involved in written reports on monitoring and evaluation of progress on reaching universal access targets, civil society participation, and minimum standards implementation. Involvement could take the form of researching, writing and/or final approving.</td>
<td>Institutional development and capacity-building support is occurring (ongoing programs / workshops) in order to improve the capacity of civil society to represent their constituencies; Institutional development and capacity-building support is occurring (ongoing programs / workshops) in order to improve the capacity of civil society to collaborate with the government and its agencies in universal access processes; Institutional development and capacity-building support is occurring (ongoing or one-off training programs or workshops) in order to improve civil society capacity to strengthen their networks;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 2f. Score sheet

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Stage</th>
<th>Score by CS (^{16})</th>
<th>Score by GOs (^{17})</th>
<th>Agreed Score (^{18})</th>
<th>Final score (^{19})</th>
<th>Recommended action Actor, timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>I: Establishment of universal access processes / target-setting</td>
<td>1 Planning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 Decision-making and Agreements</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 Representation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>II: Implementing, Monitoring and Evaluating</td>
<td>1 Planning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 Decision-making and Agreements</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 Representation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>III: Resources</td>
<td>1 Planning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 Decision-making and Agreements</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 Representation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 2g. Implementing Minimum Standards

This is an example of how Minimum Standards proposal can be implemented:

- Government and civil society representatives agree to implement the minimum standards proposal.
- Referring to the proposed matrix below, each group has a facilitated discussion to evaluate progress in each of the categories. They also agree on or affirm a score to be used as a minimum standard.
- The groups come together and share the results of their discussion.
- In this country, they agree to focus on seven of the nine categories, excluding discussion of ‘consultations’ (planning & UA establishment) and that they will consider ‘representation’ for the two stages of ‘establishment’ and ‘implementation’ as one category.
- They decided to focus discussion on two categories, the ‘decision-making and agreements’ stage of ‘establishment of UA processes/target setting’ and ‘representation’ as it pertains to ‘resources’.
- For ‘decision-making and agreements’ for the ‘establishment of UA processes/target setting’, there are six indicators listed.
  - Civil society and government agree that the national plan includes civil society participation.

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\(^{18}\) The final agreed score between civil society and government could be an average of the two scores, or a score that is negotiated and agreed upon by both parties.

\(^{19}\) The final score is recommended to be the average of the three agreed scores for each of the three aspects of Universal Access.
None of the other indicators are in place.

Civil society’s starting point is that all six are necessary represented by the minimum standard score of (4).

The government’s starting point is that signing an MOU is sufficient, which represents “progress occurring.” They advocate for 3 indicators achieved, translating to a minimum standard score of (2).

After negotiation, they agree to accept one out of the first two indicators, and that this also then fulfils the last indicator (“agreement on minimum standards”).

They agree to aim to achieve 5 indicators, which will represent a score of (3): partnership, or ‘agreements made but not fully enforced.’

For ‘representation’ pertaining to ‘resources’:

It is agreed by both parties that civil society is already included on the national aids council that makes most of the decisions with 6 civil society representatives out of 18, of which 3 are PLHIV, and 4 represent affected communities.

While civil society feels that it does not have full participation in government decisions (independent of the NAC) on resource allocation, they agree that this issue is not as much importance as others, and that they will advocate for a minimum standard score of (3) but settle for a score of (2) – ‘opportunities for input through meetings/consultations’.

In the end, the parties agree on aiming for (2), although all three indicators are fulfilled.

Both parties supply scores for the seven agreed areas and decide to use average scores as the agreed score between them. An average score is also calculated for each of the three aspects.

The final report from the meeting includes planned actions and a timeline arising from each of these discussions.
## Civil Society Participation in Universal Access Processes

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Stage</th>
<th>Score by CS</th>
<th>Score by GOs</th>
<th>Agreed Score</th>
<th>Final score</th>
<th>Recommended action Actor, timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>I: Establishment of universal access processes / target-setting</td>
<td>1 Planning</td>
<td>Agreed not to discuss</td>
<td></td>
<td></td>
<td></td>
<td>Agreed not to discuss</td>
</tr>
<tr>
<td></td>
<td>2 Decision-making and Agreements</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>2.5</td>
<td>No actions necessary</td>
</tr>
<tr>
<td></td>
<td>3 Representation</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td></td>
<td>Both parties content. Agree to write report on civil society representation for target-setting</td>
</tr>
<tr>
<td>II: Implementing, Monitoring and Evaluating</td>
<td>1 Planning</td>
<td>2</td>
<td>3</td>
<td>2.5</td>
<td></td>
<td>Agreed for civil society to take part in M&amp;E process. Civil society to monitor and follow-up.</td>
</tr>
<tr>
<td></td>
<td>2 Decision-making and Agreements</td>
<td>3</td>
<td>2</td>
<td>2.5</td>
<td></td>
<td>Agreed procedures for civil society involvement in implementation of UA projects. Follow-up consultation to be hosted by government.</td>
</tr>
<tr>
<td></td>
<td>3 Representation</td>
<td>Agreed to combine with I: 3 (above)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>II: Implementing, Monitoring and Evaluating</td>
<td>1 Planning</td>
<td>1.5</td>
<td>2</td>
<td>1.75</td>
<td></td>
<td>Need for improvement noted and to be carried over into III / 2.</td>
</tr>
<tr>
<td></td>
<td>2 Decision-making and Agreements</td>
<td>1.5</td>
<td>1.5</td>
<td>1.5</td>
<td>1.75</td>
<td>Improvement needed. Meeting scheduled to discuss resource support for civil society capacity building</td>
</tr>
<tr>
<td></td>
<td>3 Representation</td>
<td>2.5</td>
<td>1.5</td>
<td>2</td>
<td></td>
<td>Civil society to improve quality of representative within 2 months</td>
</tr>
</tbody>
</table>

A further list of actions, or agreements can be attached to the scoresheets.
PART 3: M&E AND NEXT STEPS

3a. Monitoring and Evaluation

As civil society will play a key role in monitoring universal access progress, it may be useful to review some of the processes involved:

It is crucial that civil society be a part of any monitoring of targets, as well as reporting processes on both interim 2008 targets and those for 2010, and in the production of any accompanying reports and recommendations.

In addition to being part of official national processes for overall monitoring and evaluation of achieving universal access, there may be a second option: in 2006 in preparation for the General Assembly on progress made on the UNGASS Declaration of Commitment, UNAIDS accepted ‘shadow reports’ from community sector advocates. If a similar process were to be applied to universal access processes, civil society monitoring teams, independent of official monitoring processes would report to UNAIDS on progress on reaching UA targets.

Other options for monitoring are at the regional and global level. At the February 2006 Universal Access Consultation in Pattaya, Bangkok, civil society made a recommendation to:

Establish independent monitoring bodies (‘AIDS Watch’) at regional levels to monitor government and civil society commitments and performance on HIV/AIDS.

This would be auspiced under ASEAN, SAARC, and/or the Pacific Island Forum. Meanwhile, the International Treatment Preparedness Coalition (ITPC) suggested in a letter to WHO that:

A Universal Access Strategic Planning and Monitoring Group must be set-up as a standing committee of WHO, UNAIDS, the Global Fund, PEPFAR, DFID, representatives of the other G8 countries, developing and middle-income countries, PLHIV networks, treatment activists and organisations representing key populations. It should hold its first meeting by September 2007 and continue to convene and report semi-annually until universal access to treatment, prevention and care is achieved.

In addition to this proposal, ITPC’s successful “Missing the Target” report provides another framework. For this project, research teams were formed in six countries to assess progress towards the WHO 3x5, and now the universal access, goal. Written and researched by civil society leaders, the report will add six more countries to do full research reports and seven to do summaries for 2007.20

Whether monitoring and evaluation is undertaken by multilateral agencies such as UNAIDS, or by international and regional NGOs, many of the minimum standards proposed for national processes will apply to regional processes, in particular:

- Representation of civil society organisations on any decision-making bodies
- Participation of civil society in any processes of monitoring and evaluation
- Availability of funds to regional and international CBOs, NGOs, and networks to support civil society participation.

Funding for civil society participation may come from the UN or donors, rather than national governments, though this support should be leveraged to ensure that these governments have a full commitment to the process outside of funding.

3b. Next steps

While minimum standards for civil society participation in HIV responses have been suggested in a number of fora, this is the first concrete proposal. It is intended to compliment the many efforts currently being carried out in support of civil society participation in universal access processes, which will comprise a main part of national responses to AIDS.

How these minimum standards will be used will depend on how widely they are accepted and distributed, whether civil society organisations find them useful and effective, and whether civil society is successful in advocating for their use. It will also depend on its further development by civil society. It may be useful for communities at higher risk of HIV infection (i.e. drug users, sex workers, migrants) to expand and make these mini-

mum standards more specific. Translation of the tool into other languages will be necessary for it to be used more widely.

**Next steps for Minimum Standards Proposal**

- Wide distribution to civil society and relevant stakeholders
- Meetings with UNAIDS and other key stakeholders to discuss implementation
- Endorsement by civil society groups
- Translation of the proposal
- Adaptation of proposal to address concerns of specific affected communities
- Trial proposal in countries

The use of this tool will also depend on external factors to civil society: how the UA initiative is functioning on national, regional and global levels, what opportunities are open for dialogue between civil society and other key stakeholders, and amidst other frameworks, conceptual or real –such as the Global Fund, or the Three Ones– if universal access is the most useful focal point for civil society advocacy and activity.

A process of endorsement by civil society and other partners may encourage the use of these standards by national governments. National workshops and consultations would be useful to agree on and develop this tool for individual countries.

National reporting on attaining these minimum standards will need to provide a description of the full context in which the report is being written, for a report should measure **progress**, rather than success or failure. If a country has had no civil society involvement in national AIDS responses, the minimum standards proposed here may still be too high. Their progress should be recognised at the same time that this proposal can show them their future desired direction.

If this proposal is implemented, it will be useful to evaluate how it was useful at the national level, whether there were problems of implementation, and what changes should be made for future versions. This proposal is a work in progress. As civil society participation improves across the Asia Pacific region, we hope that a “minimum standard” will be used in a dynamic, rather than static manner, moving from strength to strength in how the world responds to HIV and AIDS.
Appendix 1: Background

Introduction

In August 2006, the UNAIDS Regional Support Team Asia and the Pacific (RST-AP) convened a regional civil society consultation in Bangkok, Thailand. The consultation gathered representatives from regional and national networks and organisations working on HIV and AIDS in the Asia Pacific region to explore strategies and mechanisms to facilitate stronger civil society participation in universal access processes.

The participants concluded that there is a need to strengthen civil society participation in all processes of the initiative. This can only be accomplished through prerequisites such as:

- documentation of good practices and challenges;
- capacity building and resource mobilisation for civil society groups;
- adequate planning and preparation by all stakeholders for civil society participation; and
- the development of minimum standards for civil society involvement.21

As a result of the last recommendation, UNAIDS RST-AP contracted the Coalition of Asia Pacific Regional Networks on HIV/AIDS (The Seven Sisters)22 to produce a document, a proposal for minimum standards for civil society participation in universal access processes, through a consultative process including an in-person regional meeting. While the focus of this document will be the Asia Pacific region, it is hoped that other regions in the world will find it useful.23

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It is also important to note the differences in political and cultural contexts between countries in Asia alone. Much of this document presupposes a functioning civil society and will be difficult to implement in countries where this does not exist.24

What is civil society?

There are many definitions of civil society, but they generally agree that civil society is the dimension of society that is different from the “state” and is important as a forum for independent public expression. In its common usage in the world of AIDS, civil society refers to people living with HIV and their organisations, community-based organisations, non-governmental organisations working at local, national, regional or international levels, AIDS service organisations, and faith-based organisations.

What is Universal Access?

The universal access (UA) initiative refers to the commitment by United Nations member states to scale up HIV prevention, treatment, care and support to reach all who need it by 2010. It is key to achieving the Millennium Development Goal on HIV/AIDS25 – to halt and reverse the spread of the epidemic by 2015.

Building on the earlier World Health Organisation’s “3 x 5” initiative to reach 3 million people with antiretroviral therapy by 2005, the UA initiative was proposed at the July 2005 Gleneagles meeting of the Group of Eight and affirmed by the United Nations at their World Summit in September. Following a December UN General Assembly resolution, consultations were held in early 2006 in seven regions, and in more than 100 low- and middle-income countries. The UNAIDS secretariat also convened a multipartner Global Steering Committee.

As a result, UNAIDS identified six requirements to achieve universal access, summarised as follows: 1. National AIDS plans to be developed 2. Obtaining sustainable funds to fund these plans 3. Strengthen human resources to carry out these plans 4. Remove barriers to accessibility to the tools of HIV prevention, care and treatment (such as condoms, or AIDS treatment) 5. Protect the human rights of PLHIV and vulnerable peoples, and promote their involvement in the response. The 6th point should be read in full for its relevance to this document:

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22 Sponsored by UNAIDS; Fiscal Manager: APCASO; Author: Andy Quan, Australian Federation of AIDS Organisations (AFAO). This paper benefited particularly from the advice and hard work of Gerard de Kort and Susan Chong.
23 The methodology of how this consultancy was carried out is found in Appendix 3
24 A discussion on building civil society capacity, particularly in countries where this is weak, is beyond the scope of this consultancy.
25 As adopted at the UN World Summit September 2000.
Targets and accountability: Every country should set in 2006 ambitious AIDS targets that reflect the urgent need to massively scale up HIV prevention, treatment, care and support and move as close as possible to the goal of universal access by 2010.

The Political Declaration on HIV and AIDS from the 2006 High Level Meeting on AIDS (31 May–2 June)²⁶ embraced the principle of moving towards universal access. It committed UN Member States to:

- pursuing all necessary efforts to scale up nationally driven, sustainable and comprehensive responses to achieve broad multi-sectoral coverage for prevention, treatment, care and support, with full and active participation of people living with HIV, vulnerable groups, most affected communities, civil society and the private sector, towards the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010.

Since then, countries have been developing and revising national AIDS plans and targets for scaling up towards universal access. Other processes related to universal access will include the implementation of these national plans, and monitoring of the success of their implementation at national, regional and global levels. While universal access can be considered an overall framework or goal, there are not separate and specific universal access processes: the goal will be achieved through existing processes such as national AIDS strategies and Global Fund grants.

Another framework which will have an influence is the ‘Three Ones’, to the extent that it is adopted in each country. At a meeting in April 2004, donors, developing countries and UN agencies agreed to three core principles to coordinate the scale-up of national AIDS responses, the ‘Three Ones’: one agreed AIDS action framework, one national AIDS coordinating authority, and one agreed monitoring and evaluation system, all underpinned by a commitment to a broad-based multi-sectoral approach that includes civil society partners.²⁷

The necessity of civil society participation

Civil society participation is a process through which civil society influences and shares control over initiatives, decisions, and resources that affect the segment of society which they represent by being meaningfully involved in all phases of planning, dissemination, implementation, and monitoring and evaluation of policies and programs.

UN member states have already committed themselves to the involvement of civil society in working towards the goal of universal access. It will require the “full and active participation of people living with HIV, vulnerable groups, most affected communities, civil society and the private sector.”²⁸ Meanwhile, UNAIDS noted that “the participation of a wide range of stakeholders—especially civil society and people living with HIV—is critical to [the universal access initiative’s] elaboration and success.”

It has been shown around the world that the most effective responses to HIV and AIDS in prevention, care and treatment involve those who are affected by the disease. If civil society is an equal partner, responses to the HIV and AIDS epidemic will be more sustainable and effective.²⁹

To improve HIV prevention, it must be remembered that the transmission of HIV is the result of consensual and intimate behaviours such as unprotected sex or sharing of injecting equipment. These are complex and mostly private behaviours. The experts on these issues will not be government officials or ministries of health. They will be the people who are engaging in these activities, for example, injecting drug users who will understand issues surrounding drug use. As behaviour-change will take place on a personal level and at a community level, these local experts ensure that interventions are applicable to local settings. Their commitment and support will strengthen the intervention and their participation both as target communities and program implementers will ensure that the intervention is accepted. All of these factors will contribute to sustainability. The same is to be said for treatment, care and support programs, particularly regarding the meaningful involvement of PLHIV and NGOs who will understand the community issues which national responses should be built on.

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²⁶ A follow-up to the meeting five years earlier that produced the Declaration of Commitment on HIV/AIDS
²⁷ UNAIDS, ‘The ‘Three Ones’ Key Principles, 2004
²⁹ More on involving affected communities in responding to HIV/AIDS can be found in: Seven Sisters, “All of Us Count” (2003)
Responses to HIV and AIDS involve people and communities. Scaling-up local responses to the level needed for universal access is an enormous task. Solutions imposed from outside of these communities are unlikely to work. Civil society involvement is needed to establish ownership, accountability and transparency. It will be crucial to many aspects of universal access:

- Agreeing on programs to be scaled up and how to implement them;
- Participating in target-setting so that the specific dynamics of the national epidemic will be addressed;
- Agreeing which populations to be prioritised;
- To drive forward monitoring of progress and holding stakeholders accountable to set targets.30

However, to date, civil society participation in universal access processes has been varied with reports of exclusion or insufficient levels of involvement. ICASO is currently working on a report on the involvement of civil society in national target-setting. The report is due for June 2006 and will highlight a range of country experiences, which include countries where civil society participation was limited. UNAIDS reports that in some countries, “civil society involvement has often been largely limited to major organisations...[i]n some instances, civil society was not invited to join the target setting at all.” 31

Most countries were set to meet the deadline of the end of 2006 for setting targets, but some were scheduled to set targets during the first months of 2007 to correspond with their national strategic planning cycle. Civil society participation is still needed for any countries yet to complete target-setting, and will be necessary, in all countries, to evaluate the targets set and participate in a process to revise targets, if necessary. Without civil society participation, targets may be inaccurate or unrealistic:

...civil society is well placed to comment on the feasibility, relevance and cost of proposed targets and activities. People living with HIV, representatives of most-at-risk populations or those who assist them can provide comprehensive information on the specific behaviour patterns that may be driving the epidemic in a country and how best to reach their constituency with targeted and effective services.32

Challenges to civil society participation

While national governments, by signing onto the UN-GASS declaration, have declared a commitment to civil society participation in their response to HIV and AIDS, this has not always been translated into reality. In practice, civil society faces numerous challenges from governments who are uncommitted or uninterested in their participation, who don’t understand the benefits of civil society participation, or who actively discourage it in order to maintain control over decision-making processes. Negative scenarios include:

- Processes of consultation where civil society input is not authentic, or carried into decision-making processes;
- When civil society is not accepted as an equal and valued member in the response;
- Token representation in processes where representatives do not have the power to negotiate or speak;
- When representatives are influenced or coerced in their opinions, or co-opted into government decisions;
- When civil society representatives cannot participate in processes authentically because they lack resources: human resources, finances, information or preparation time;
- When civil society groups or representatives are invited to participate because they are easy to work with while controversial ones, more willing to raise viewpoints opposing to the government, are excluded;
- When selected representatives do not have the capacity to represent a specific or general community group.

This marginalisation or exclusion from decision-making could take place in any stage of universal access processes: planning, target-setting, implementation, and monitoring and evaluation.

30 UNAIDS, “Universal Access Targets and Civil Society Organisations, a briefing for civil society organisations.” November 2006
A major obstacle to civil society participation is in countries where civil society is nascent or immature. While some countries in Asia, such as Thailand and the Philippines, have developed civil society movements that includes NGOs and community organisations, other countries such as Laos, Vietnam, Myanmar and China have national histories where community mobilisation was discouraged by law. For example, in Vietnam, support groups of people with AIDS must be classified as self-help groups rather than NGOs or community organisations, and independent, local NGOs do not exist. Government-controlled or -influenced NGOs represent civil society. In these situations, this document, which requires functioning, independent civil society organisations to advocate for and implement its recommendations, may not be of immediate practical use.

In other countries where civil society is still developing, the ability for civil society to participate in universal access processes will be affected by a range of factors. Many NGOs and CBOs are involved in substantial work in local communities but are inexperienced at national level policy-making. Do they have the capacity to engage in discussions of and take part in monitoring and evaluation, strategic thinking, watchdogging and advocacy? Other organisations may be too concerned with their own political and financial stability to take part in larger processes. Also, civil society represents a broad range of groups. Do they collaborate or fight with each other? There may be conflict resulting from competition for community-allocated positions on committees.

Civil society participation is hindered as well where affected communities face stigma and discrimination. This lack of what is sometimes called “an enabling environment” means that marginalised, at-risk populations will not or cannot participate in national processes. Drug use, sex work, and sex between men are illegal in many countries. In these circumstances, representatives will lack willingness and capacity to be involved. This situation also applies to the protection and promotion of the rights of people living with HIV. Protective legislation combined with the implementation of good policy and public education could mean the difference between the involvement of PLHIV being facilitated rather than disabled.

A final challenge to civil society participation in universal access processes is whether the initiative as a whole is functioning. The estimated necessary resources have not been attained. At the June 2007 G8 summit in Germany, it was hoped that G8 countries to honor their commitment to pledges made in at the 2005 Gleneagles summit by increasing funding for universal access, and presenting a funding plan with specific resource commitments. This did not happen and the $60 billion pledged will not meet $192 billion estimated by the UN that is needed to address AIDS, TB and malaria from 2008 to 2012, mostly for HIV/AIDS.

Meanwhile, countries are failing to commit to the UA initiative. By the end of October 2006, 84 countries \(^{34}\) reported that they had set universal access targets, of which only 44 have set outcome targets for all three programmatic areas of prevention, treatment and care and support.\(^{35}\) Only 26 have provided targets linked to

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33 Joint comments from Khartini Slamah and Keo Tha to organisers of Joint UNFPA/WHO
34 Out of 100 countries that participated in target setting, and out of 192 Member States in the United Nations. (“Analysis for the International HIV/AIDS Alliance on the Universal Access Targets”
costed national plans for key HIV/AIDS interventions. In Asia and the Pacific, UNAIDS assessed progress in 18 countries on target-setting as follows (as of October 2006):

- Fast-moving: Cambodia, India, Philippines, Nepal and Thailand
- Slow but moving: Bangladesh, Indonesia, China, Laos, Vietnam, Myanmar and Sri Lanka
- Challenging: Pakistan, Fiji, Papua New Guinea, Mongolia, Malaysia and Timor Leste.

At the same time, the Alliance comments that universal access targets “may... remain unmet because of the barriers that stigma and discrimination present”:

Those most in need of HIV information, prevention, and treatment are being driven underground, while people living with HIV experience stigmatisation and discrimination, including at work, and in accessing government services.

Finally, rather than a challenge, we note one possible downside to civil society involvement: the tendency of some governments to let civil society organisations implement tasks or take responsibilities for what the government should be doing itself.

**Previous Discussions on Minimum Standards**

The concept of minimum standards are used in a broad range of fields. The United Nations has adopted standard minimum rules for the treatment of prisoners. Minimum information standards require a minimum amount of data required to meet a specific set of aims. The International Labour Organisation has established minimum standards for social security.

Standards are sometimes divided into three tiers: a minimum standard, where an organisation or process receives a certification or endorsement if it fulfills an agreed set of indicators; target standards which represent aspirational goals, and benchmarking standards which describe excellence or best practices that can be emulated by others.

For the purpose of this paper, we will define “minimum standards for civil society participation” as a minimum set of requirements, actions, conditions or adherence to principles that must be met and agreed to by civil society and government. It may be a challenge to get government to agree to this process, and the first stage may be for AIDS-affected civil society to define itself and then endorse the minimum standards themselves.

However, to date, there are no popular or widely disseminated standards or benchmarks to measure civil society participation in national or international processes. Some multilateral institutions have made moves towards the concept of “minimum standards” but without concrete results. For example, a recommendation for the Asian Development Bank in their ADB-Government-NGO Cooperation: A Framework for Action (2003-5) was that participation by NGOs in ADB processes could be institutionalised and codified by formalizing guidelines, including minimum standards for participation. While the ADB has developed policies on working with NGOs and a staff handbook for doing consultation and participation, no document outlining minimum standards was ever produced.

In considering civil society participation in the development of Poverty Reduction Strategies (PRS), it was noted:

The IMF and World Bank have not set any minimum standards for participation by social actors, but rather evaluate participation in relation to existing participatory practises in the respective country.

In their recent ‘Policy Brief on the Greater Involvement of People living with HIV (GIPA)’ (March 2007), UNAIDS established as a policy position that governments, international agencies and civil society must “set, implement and monitor minimum targets for the participation of people living with HIV, including women, young people and marginalised populations, in decision-making bodies.”

These proposed minimum standards are therefore a starting point for creating standardised data on civil society participation in responses to AIDS, intending to serve as a basis for policy-making and planning.

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41 Eberlei, Walter, Dr. “Institutionalised Participation in Processes Beyond the PRSP” September 2001.
Models of Civil Society Participation

Civil society participation in universal access processes will depend on which national structures are used to establish or implement them. While civil society may be involved in implementation of projects or in monitoring and evaluation, the most crucial involvement will be in participating in decision-making processes. This will require cooperation from the government as well as internal processes to select representatives for civil society. This section will consider these issues, as well as present models for civil society involvement in national responses to HIV and AIDS.

Guidelines have recently been produced by ICASO, AfriCASO and the International HIV/AIDS Alliance on the active and meaningful involvement of the community sector in the coordination of national AIDS responses. The key steps listed, including such actions as developing terms of reference, selecting representatives, and providing induction for community members on national coordinating bodies, are all relevant to universal access initiatives, which will necessarily be a part of the development and management of national AIDS strategies. The bodies that will manage or be involved with these processes may include:

- A National AIDS Coordinating Authority with a broad-based multi-sectoral mandate
- The ministry or department of health that is responsible for HIV/AIDS
- A broad-based national partnership forum (as recommended as part of the ‘Three Ones’)

Participation by civil society will be necessary on all these bodies and could take the form of:

- Permanent representation by civil society on relevant bodies
- Representation by civil society on task forces for each of the processes related to universal access (i.e. target-setting, monitoring and evaluation)

This process will pose challenges to civil society in terms of how they select representatives. Where there are legitimate and accepted national umbrella AIDS NGO and PLHIV organisations, and other networks representing affected communities, these organisations can appoint representatives, although this may exclude smaller CBOs and NGOs. In countries without clear national bodies or networks, it will likely be difficult to set up clear selection processes. In either situation, there will be numerous areas of concerns, such as:

- Ensuring that representatives are elected by civil society rather than appointed through national sectors;
- Ensuring a balance of civil society representation taking into consideration issues such as geography, types and size of organisations, gender, representation of marginalised populations and PLHIV, and a country’s epidemiological profile;
- Developing simple and practical systems for selection of representatives, with as much consensus as possible, where no, or weak, national or umbrella organisations exist.

Additional tasks would be:

- Agreeing to an appropriate number of or percentage of civil society representatives and negotiating or advocating for it;
- Agreeing to optimum terms for representation, and how representatives will work with each other;
- Agreeing to an appropriate level of communication and information sharing with constituents, which may require going beyond an NGO’s usual membership or audience.

The issue of selecting community representatives is also discussed in the main body of this proposal.

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42 ICASO, Afrcaso and the Alliance, “Coordinating with Communities”, 2007.
43 All of these points from or adapted from: International HIV/AIDS Alliance and ICASO, Discussion paper: Civil Society and the ‘Three Ones’. April 2005.
Some tips on getting involved with universal access

Does your civil society organisation want to be involved with the universal access process? What benefit will it bring to your organisation? What benefits can you bring to the process? If you can identify positive reasons to be involved, what actions can you take?

➢ Research and map who is involved in universal access platforms in your country. For the government, who is responsible? The Ministry of Health? A department of the ministry? Another body? Are any NGOs active on this issue? What activities are they involved in?
➢ Work with peak body or umbrella organisations in your country to influence the relevant bodies (i.e. the Ministry of Health, active NGOs);
➢ If there is no peak body or umbrella organisation, make a coalition with other civil society groups;
➢ Request assistance from UNAIDS Country Offices or Focal Points or the Theme Group Chair, or in countries with no such contacts, the UNAIDS Regional Support Team for Asia and the Pacific (please contact the Seven Sisters Secretariat if you need assistance to find an up-to-date contact).
➢ Develop an advocacy strategy for how you want to be involved and what you want to achieve;
➢ Formulate recommendations and publicise and share them widely.

Global Fund recommends that the CCMs membership include a minimum of 40% civil society representation from NGOs, CBOs, affected communities, faith-based organisations, academia and the private sector. Membership of CCMs range from below ten members to over forty. After grant approval, the CCMs oversee the progress of the implementation of programs.

If a partnership forum has already been established, as part of the ‘Three Ones’ or as a Global Fund Country Coordinating Mechanism, it could be used or adapted to manage universal access processes. If a new committee were to be set up, there would need to be clear justification to do so. Any or all of these structures could host broader consultation meetings on a periodic basis.

Even with NGO representation on CCMs, there can be challenges to their participation. An analysis from 2002 by the Alliance found that effective participation was limited at times through inaccessibility of information, and that involvement could be limited to consultation rather than as partners in the decision-making process. Meanwhile, a 2004 report from ICASO found inadequate representation of NGOs and vulnerable populations on CCMs, civil society representatives not being treated as full partners, and the roles of CCM members ill-defined. Some civil society representatives were not truly representative and some lacked skills to participate fully. Participating in this process created a crisis for some NGOs in terms of the human and financial resources required to participate on CCMs. Finally, in some countries, government NGOs (GONGOs) occupy seats that should be instead filled by independent NGOs or community representatives.

It is also useful to look at examples of national bodies or mechanisms used to response to HIV and AIDS, and how they involve civil society. The Global Fund Country Coordinating Mechanisms (CCMs) provides one example of a mechanism that could be used to oversee universal access processes. These country-level partnerships were designed to encourage participatory decision-making and local ownership. CCMs develop and submit grant proposals to the Global Fund. Based on a principle of broad representation, the
However, there are positive examples of collaboration between government and communities. In late 2006, Senegal was given three months to resolve difficulties related to their Global Fund grant, specifically concerns about funding new projects “whose quality had not been validated.” To restructure their management, a structure was implemented with two Principal Recipients, one of who is responsible for the civil society component. The Global Fund was sufficiently impressed to “strengthen civil society engagement, particularly people living with HIV in the entire scaling up process, from planning to implementation.”48 In this light, it will be useful to work with and request support from UNAIDS whenever needed.

Beyond the global fund, there are good practice models of partnerships with communities in national AIDS responses, for example, in the Philippines where they have also been addressing issues related to universal access.

The Philippines also provides a useful model for civil society involvement in their national response to HIV. There is a vibrant and established NGO community working on HIV and AIDS issues in various parts of the country and they have taken it upon themselves to proactively engage in various national and local processes in the HIV response. Examples of their involvement include the development of GFATM proposals (rounds 3, 5, 6) and its subsequent implementation; the development of the UNGASS reports; the crafting of the 4th AIDS Medium Term Plan (2006-2010) and the subsequent two-year operational plan; the development of national monitoring and evaluation targets and indicators; and the formation of Local AIDS Councils. From late December 2005 to March 2006, the government of the Philippines undertook a series of initiatives to develop its universal access targets and roadmap. This process included the full participation of civil society. One of the agreed targets included a strategy to improve the engagement of faith-based organisations, media and business.


Civil society participation can also take the form of consultations on a periodic basis or as major one-off events. It is generally agreed by civil society organisations that consultation alone is insufficient: civil society must be able to take a greater role in decision-making. However, consultations can be a way to supplement other types of involvement, or can be a part of a process towards meaningful participation. Used effectively, consultations would reach as broad a range of stakeholders as possible.

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Consultations and meetings may form part of decision making in all processes related to universal access. As the achievement of universal access targets will require the collaboration of a broad range of stakeholders, it may be desirable, particularly in areas such as monitoring and evaluation, to hold consultations or meetings with a wider range of participants than is possible on smaller decision-making bodies.\(^{50}\)

The model of Community Advisory Boards (CABs) was developed in the 1980s, arising from the demands of North American and European AIDS activists to be involved in clinical trials for AIDS drugs. While early CABs were mostly composed of people living with HIV, recent CABs are made up of representatives from a range of affected communities and have been used not only for treatment trials but for preventative trials such as HIV vaccines and microbicides. The CAB model may be useful where umbrella NGO organisations do not exist. It could also be used as a way of creating a broader multi-sectoral consultative body which could be used to advise a smaller number of civil society representatives who are sitting on a national coordinating mechanism.\(^{50}\)

\(^{50}\) For some recommendations on how consultations should be conducted, see: The European Commission, “Development of relations between the Commission and civil society”: http://europa.eu/scadplus/leg/en/cha/c10717.htm
APPENDIX 2: RESOURCES

Key resources for understanding universal access:


Key resources for understanding civil society (community sector) involvement in national and international responses to HIV and AIDS.

- Seven Sisters, “All of Us Count” (2003)
- UNAIDS, ‘The ‘Three Ones’ Key Principles, 2004

Background discussion for Minimum Standards Proposal and Civil Society Participation (general)

- Eberlei, Dr. Walter “Institutionalised Participation in Processes Beyond the PRSP” September 2001.
- UNESCAP, Social Development Division, Youth Participation Manual, 1999
This consultancy was initiated in March 2007. A management team from the Seven Sisters coalition was formed consisting of Malu Marin, Vince Crisostomo, and Susan Chong, and the consultant, Andy Quan (Australian Federation of AIDS Organisations), was hired. Calls for expression of interest to be on the Advisory Board for this project was sent to Asia-Pacific participants of the August 2006 Regional Civil Society Consultation on universal access.

An advisory board of nine members was formed with the key responsibility to advise on the development of the minimum standards proposal.

Promboon Panitchapakdi; Thailand
Luisa Tora; Fiji
Maura Mea; Papua New Guinea
Rachel Ong; China
Gerard de Kort; Bali, Indonesia
Glenn Cruz; Phillipines
Greg Gray; Bangkok, Thailand
Shiba Phurailatpam, Thailand
Khartini Slamah; Malaysia

A draft paper was produced and circulated to the advisory board, as well as the participants of the Regional Civil Society Consultation. The paper was revised according to comments received and a new draft was sent out preceding a regional consultation on minimum standards held in Bangkok 1 – 2 June 2007 with 25 participants. The list of attendees is found in Appendix 4.

Recommendations from the consultation were incorporated into a new draft of the proposal, which was circulated a final time to meeting participants and other key advisors. The final draft was submitted to UNAIDS Regional Support Team Asia and the Pacific in July 2007.
APPENDIX 4: REGIONAL CONSULTATION PARTICIPANTS

1-2 JUNE 2007 REGIONAL CONSULTATION LIST OF ATTENDEES
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