When asked, **communities** answer!

Asia Regional Civil Consultation for
Commision on AIDS in Asia

APN⁺
asia pacific
network
of people living
with hiv/aids

hdn
Health & Development
Networks

When asked, **communities** answer!

Asia Regional Civil Consultation for Commision on AIDS in Asia

Communities comprise the glue that holds people together. The key to achieving health in the community is based not only on getting services to the community, but also engaging and empowering them to be the catalysts of change and bearers of success.
—*The Global Health Council*

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Introduction

> " To address HIV-related stigma, we must turn to those who live with HIV. Their courage and expertise have given me new and invaluable insights into the epidemic. "

- Ban Ki Moon, UN Secretariat General, during his speech of the Launch of Commission on AIDS in Asia report, 26 March 2008, New York

When I was asked to join the Commission on AIDS in Asia (CAA), I thought that I could either take this chance to bring out the voices of HIV/AIDS community and people iving with HIV that I represent or simply let the opportunity slip away.

It was in December 2006 when I was invited to participate. The Commission was already one third through the process. Originally the process was to include both the Asia and Pacific regions jointly. As the needs and varied contexts of Asia and the Pacific were brought to light, the decision was taken to split the two regions. The Asia Commission stands on its own. I joined the first meeting in January 2007 in Jakarta.

It was terrifying to sit down with people from academic and politic backgrounds. However, I could see this as an opportunity to make a difference and to really highlight both the achievements as well as the persistent limitations of civil society, particularly in (southeast) Asia. It is here that social and cultural norms prevent most people from speaking out about their status or related behaviours. Highlighting what works and what doesn't would be a challenge. I believe that "communities are the glue that holds people together."

The key to achieving health in the community is based not only on getting services to the people, but also engaging and empowering them to be the catalysts of change and bearers of success.

This was where I could learn and practice what has always been called as GIPA (the Greater Involvement of PLHIV) at another level.

As the only civil society representative out of the nine Commission members, this is where the word "accountability" comes into the context. The burden was not easy, having to voice out what the reality of what is happening on the ground, voicing the reality of lives when people are so used to talking about academic and scientific evidence and justification.

I wanted to ensure that there was enough authentic evidence by bringing issues that were voiced by others, not just me.

In a short time, about one month, consultations with civil society and community representatives were required to engage as many people as possible in the process. Face-to-face consultation was not enough. On-line surveys and consultation came onto the horizon.

Advocacy, lobbying and gathering support to make the idea a reality were conducted. With documentation I was able to share the experience in engaging communities and making sure that these communities' voices were heard and we were all more accountable. The responses and support were huge and these gave me more confidence as someone who simply sees herself as just one of the people living with HIV.

I'd like to give a special thanks to those people who supported this idea from the beginning, and to all of the people who gave of their time, commitment, and experiences with open hearts.

I hope that with this document I can share my experience that engaging communities works. It is possible, and this document highlights one of the practical ways how.

When we have the intention to be accountable and when asked, communities definitely answer!

Frika Chia Iskandar
Civil Society Representative
Commission on AIDS in Asia

The Process:
Civil Society Consultation on AIDS in Asia

Background on the Commission on AIDS in Asia

The Commission on AIDS in Asia (CAA) was an independent body established in July 2006 and chaired by Dr Chakravarthi Rangarajan, Chairman of the Economic Advisory Council to the Prime Minister of India. It brought together nine of the region's leading development economists, epidemiologists, policy-makers and civil society representatives working on the HIV epidemic.

Over a period of 18 months, the Commission conducted a thorough analysis of the developmental consequences of the AIDS epidemic in the region, and its medium- to long-term implications on the socio-economic environment. These findings were summarized in a report, *Report of the Commission on AIDS in Asia, Redefining AIDS in Asia: Crafting an Effective Response*, presented to the UN Secretary General in March 2008, with recommendations for a set of measures designed to mobilize leaders to adequately respond to the epidemic in the region. This process coincided with other HIV-related global and regional processes that are too extensive to review here.

" The unique feature of Community involvement in the AIDS Commission is the strong and effective presence and participation of Frika Iskandar as a member of the Commision. Frika has arranged a community consultation which is innovative, participatory and exhaustive. About 600 community members and organizations were contacted through networks and key informant interviews. The feedback was consolidated by a professional agency and made available to the Commission as the summed up views and expectations of the communities from the Commission Report. The general feedback the Commission obtained from formal and informal community views is that the Report has greatly met their expectations in presenting their point of view in a clear and unequivocal manner. "

- JVR Prasada Rao, UNAIDS, Regional Support Team Director for Asia and the Pacific

The Civil Society Consultation on AIDS in Asia

The Civil Society Representative of the Commission on AIDS in Asia aimed to help ensure that civil society opinion and input from the region was fully incorporated into the work it was mandated to accomplish. Frika Chia Iskandar, who was the only civil society representative on the Commission, was entrusted to give the civil society voice and perspective into the CAA recommendations.

It was recognized that the voices of wider community were necessary to influence the development of the CAA recommendations and to ensure that civil society's key AIDS priorities were clearly represented in the final recommendations and supported by a body of evidence from a broad range of stakeholders. The CAA recommendations could ultimately change how governments develop and make decisions about national AIDS policies and programmes. Frika worked with Health & Development Networks (HDN), with the support from the United Nations Joint Programme on HIV/AIDS (UNAIDS) Regional Support Team Asia-Pacific, to organize a realistic, open, unbiased and practical strategy for civil society consultation to reach out to as many different AIDS stakeholders as possible in the Asia region.

The **objectives** of the Civil Society Consultation were:

(1) To create a regional platform for dialogue to help ensure that civil society is involved in contributing to the Commission on AIDS in Asia's work;

(2) To assist the Commission in collecting broader and more in-depth inputs and opinions from civil society in the region, to help shape its major recommendations;

(3) To help establish links between the work of the Commission – and the current (and past) regional civil society AIDS-related consultations – to other processes and opportunities for civil society input and mobilization around:

     a. Regional events, such as the International Conference on AIDS in Asia and the Pacific (ICAAP);

     b. Regional preparations for the national UNGASS2008 evaluation report process;

     c. Assessment of progress with development of national Universal Access 'road maps', including, where possible, specific national HIV- and AIDS-related target-setting;

     d. Other global structures and relevant delegations to the Board of the Global Fund Against AIDS, TB and Malaria (GFATM), the UNAIDS Programme Coordinating Board (PCB) and the Stop-TB Partnership Coordinating Board.

> " We have to build better partnership, sustainable partnership, meaningful partnership between the government and civil society. "
>
> *- Nenet Ortega, Philippines*

> " What was important for me from this on-line survey was, as someone who's representing people living with HIV and community in this Commission, having to sit with people such as politicians, epidemiologist, professors, it makes me feel small sometimes and affects my self-confidence. Through the consultation's face to face or online surveys (where's there's evidence), I feel that I have more support from my community, that I'm also voicing out other people's voices, not only mine; This way, as community representative, I'm also learning more about accountability. "

– Frika Chia Iskandar
Civil Society Representative, Commission on AIDS in Asia

Methodology

The civil society consultation was conducted in three stages:

1) Face-to-face civil society consultation

2) Online consultation

3) In-depth key informant interviews

The civil society consultation covered at least 25 countries across Asia. It was comprised of a regional stakeholder perception and priority survey engaging more than 600 respondents from 26 countries (July 2007), and input from 85 in-depth key-informant interviews (August 2007), as well as face-to-face consultation in three countries.

Face-to-Face Consultation

During the course of its work, the Commission on AIDS in Asia invited members of civil society to share their experiences with work in HIV in their own countries. Usually after each meeting of the AIDS Commission a session of one to two hours was spent talking with community representatives in the country, and those who came for the sub-regional workshops of the Commission, to hear about the issues to be raised from the field/grassroots organizations as considerations to be included in the Commission's report

The first of these meetings coincided with the Second Meeting of the Commission in Jakarta in January 2007. At this meeting over 20 members of communities, nongovernmental organizations and academia were invited to share their perspectives of the epidemic in their country. Seven members of the Commission listened as they described the challenges faced in Indonesia.

The Commission also met members of civil society from a range of countries throughout the region through two sub-regional workshops for South and Southeast Asia.

At the Southeast Asia sub-regional workshop, held in Manila in March 2007, the Commission invited civil society representatives from Cambodia, China, Myanmar, Philippines, Thailand and Vietnam to a private, closed-door session. In this animated two-hour discussion many community representatives shared the challenges and difficulties they faced in the AIDS response in their respective countries.

At the second sub-regional workshop held in Dhaka, Bangladesh, in May 2007, representatives from over 30 different organizations representing the local most-at-risk and infected communities, as well as other nongovernmental organizations, met with the Commission. In the meeting the group presented their work and recommendations for the Commission's consideration. It was at this meeting, where some of the Commissioners also heard life experience sharing from sex worker organizations and their problems with lack of financing, as described in the 'Community' chapter of the Commission's Report.

Online survey/consultation

A **survey** is a method of gathering information from a sample of people from a larger group. Surveys find out about people's opinions and perceptions on specific topics. An online survey is where the information is gathered from people responding to the questions using an internet-based data collection method.

Benefits of online surveys

- Faster and better response rates;
- Cost effectiveness, low cost – wide reach;
- Easier to process the data collected because the information can be directly downloaded into a database;
- Various question patterns and types can be programmed to collect multi-dimensional data;
- Participants are more likely to contribute more genuine answers to the questions because of the anonymous interface.

Disadvantages of online surveys

- Reaches primarily those with internet connections and accessibility; may also depend on connectivity rates;
- People have different levels of computer experience, which may lead respondents to decline or make mistakes on their answers;
- Surveys look different on different computers and browsers so the questions may not look the same for all respondents;
- Participants may be concerned with data and privacy security;
- Self-selection may cause results to be biased by individuals with strong opinions, who have a higher tendency to respond to surveys.

The online consultation method was chosen to engage a wide range of AIDS stakeholders throughout the Asia region. The survey was designed to ensure that it was open, unbiased and accessible to people from various backgrounds and experiences. It was disseminated online using electronic discussion forums and networks.

> " The conception of civil society is going to vary enormously across Asia, and in some of the biggest countries with major epidemics, like China or Vietnam or Burma, governments do not have the same view of civil society as most of the donors... "

- Dennis Altman, Australia

Electronic forums and networks the survey announcement was sent to included:

Listservs and discussion groups

- AIDS Asia
- AIDS India
- fruitstogo listserv
- Health Gap
- International Congress on AIDS in Asia and the Pacific (ICAAP) website
- Partners Thailand
- Positive Living Working Group (PLWG)
- SEA-AIDS
- Stop-TB
- KC-Forum

Networks

- AIDS Society in Asia and the Pacific (ASAP)
- Asia Pacific Council of AIDS Service Organizations (APCASO)
- Asia Pacific Network of People Living with HIV/AIDS (APN+)
- Asia Pacific Network of Sex Workers (APNSW)
- Asia Pacific Rainbow Support Center, Inc. (AP-Rainbow)
- Asian Harm Reduction Network (AHRN)
- Body Positive – New Zealand
- Coalition of Asia Pacific Regional Networks on HIV/AIDS (Seven Sisters)
- Co-ordination of Action Research on AIDS & Mobility (CARAM Asia)
- International AIDS Alliance
- International Community of Women Living with HIV/AIDS (ICW)
- International Federation of Red Cross and Red Crescent Societies (IFRC)
- International Treatment Preparedness Coalition (ITPC)
- National country-based PLHIV and HIV-related networks
- Network of Sex Work Projects (NSWP)
- Therapeutics Research, Education, and AIDS Training in Asia (TREAT Asia)
- Women's Working Group of APN+ (WAPN)

In July 2007, as part of the civil society consultation, and in efforts to help provide inputs to the Community Representative of Commission on AIDS in Asia, Frika Iskandar, together with HDN, prepared and conducted a rapid regional consultation online survey using a web-based questionnaire. More than 600 respondents from 26 countries contributed to this survey, including people living with HIV (PLHIV) networks; local and national NGOs; international NGOs; community-based organisations (CBOs); media and journalist groups; academic/educational institutions; private sector companies; and other individuals.

The 26 countries from which the survey respondents came were:

- Afghanistan
- Australia
- Bangladesh
- Cambodia
- China
- Hong Kong
- India
- Indonesia
- Iran (Islamic Republic of)
- Japan
- Lao People's Democratic Republic
- Malaysia
- Maldives
- Mongolia
- Myanmar
- Nepal
- New Zealand
- Pakistan
- Papua New Guinea
- Philippines
- Singapore
- Sri Lanka
- Taiwan
- Thailand
- Uzbekistan
- Vietnam

The survey questions drew on the content of two previous regional civil society consultation processes and their outcomes:

1. Civil Society Statement at the conclusion of the 7th ICAAP Conference, as presented by Periasamy Kousalya (Positive Women's Network of India) on 5th July 2005;

2. Opportunities and Obstacles to Universal Access of HIV Prevention, Treatment, Care and Support Services – Report and recommendations of a regional 'Universal Access' consultation, held in February 2006 in Thailand.

The survey consisted of 16 questions, designed to:

- gauge opinions about current HIV-related priorities in the region;
- gauge the opinions of civil society (CS) stakeholders in terms of the importance and relevance of the Commission;
- identify strategies for further CS alliance-building around HIV-related advocacy; and finally,
- find out how CS partners and friends would prefer to engage with the Commission and similar processes during the remainder of 2007 and beyond.

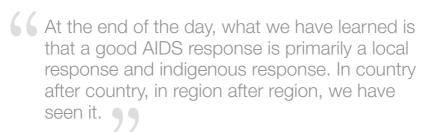## Main survey question categories covered:

- HIV services and commodities;
- legislation to address HIV-related discrimination;
- best practices and interventions for combating HIV-related stigma; and
- mechanisms ensuring accountability among key stakeholder and political commitments made towards the HIV response nationally and regionally.

The online survey was launched during the first week of July and responses were accepted until 10 July 2007. Responses were disaggregated by country and organization type, and summarized and compiled into a working paper or initial summary. Frika Iskandar, the civil society representative on the Commission, presented the summary to the Commissionto help shape its final recommendations. This report also informed the report/presentation by Ms. Iskandar at the third meeting of the Commission in Beijing on 17 July 2007.

In order to obtain the maximum response rate in the short period of time allotted, incentives were used to stimulate participation. Two survey respondents, who were chosen by their response to the survey, were supported to present their recommendations and priorities to the Chairman of the CAA at 8th International Congress on AIDS in Asia and the Pacific (ICAAP) held in Colombo, Sri Lanka, August 2007.

Communication in updating the Commission's report development was maintained through the mailing list.

It was also recognized that incentives could increase participation in surveys as many people in the HIV/AIDS sector are often over-tasked and complacent in responding to these.

" At the end of the day, what we have learned is that a good AIDS response is primarily a local response and indigenous response. In country after country, in region after region, we have seen it. "

- *Dr Anindya Chatterjee,*
  Program Director, HIV/AIDS Asia Regional Program (HAARP),
  AusAID

Summary of survey findings
Civil Society Engagement

- The AIDS response in Asia needs to integrate civil society involvement at all levels of decision-making. This includes the 'small voices' of marginalized individuals and groups and those dependently affected by AIDS policies and programmes.

- Governments, planning bodies and other decision-making entities must commit to providing/creating a safe space for civil society to dialogue around national and regional priorities and provide input.

- Civil society is a multi-sector group that represents diverse experiences and knowledge. Civil society is part of the solution, not a special interest group that has to be placated.

- All people working in HIV and AIDS are responsible for the well-being of those dependently affected by AIDS policies and programmes.

- Validity of voice needs to be considered when eliciting civil society representation and input. The louder the voice does not necessarily equate to validity or genuine representation.

> " I wholeheartedly applaud the Commission for engaging with community-based and other civil society organizations, including and especially networks of people living with HIV. The next step is to involve them directly in making HIV policies and implementing programmes. This requires strengthening the capacity of the communities and networks, and affirming a genuine commitment to involve them in a meaningful way. "

- Ban Ki Moon, UN Secretariat General, during his speech of the Launch of Commission on AIDS in Asia report, 26 March 2008, New York

HIV-related Stigma and Discrimination

- Stigma and discrimination must be addressed on all levels of policy and programmes.

- The separation of social and behavioural determinants of HIV risk and vulnerability increases HIV-related stigma.

- A human rights approach needs to be adopted across all responses to HIV and AIDS, focusing on the rights and protection of those affected.

" 90% of my organisation staff are positive. We all talk about our status openly, we are never whispering when we talk about HIV or our status. "

- Sukma Rahjvee, Indonesia

Political Commitment

- Commitments to HIV and AIDS funding must be realistic and responsive to the needs of those affected.

- Multi-sectoral collaboration and commitment within governments is necessary for an effective response. Policy and funding must be informed by various sectors and disciplines, not just epidemiology.

- Governments must be willing to contribute to and actively involve civil society increating accountability mechanisms; effectively, improving the quality and accessibility of all HIV services and commodities.

Accountability/Transparency

- Information needs to be accessible and understandable to all stakeholders.

- HIV and AIDS policies and programmes must be monitored by all stakeholders to ensure accountability and transparency.

- There needs to be mechanisms by which all stakeholders can provide comment and review national and regional policy making processes.

- True recognition of government shortcomings to address HIV and AIDS and practical effective solutions need to come from within the country, as well as from regional and international technical assistance.

Treatment

- Access to affordable or free treatment needs to be a priority for Asian governments.

- Comprehensive treatment programs should include more than just ARVs. They also need to include diagnostics, treatment for opportunistic infections, nutritional guidance and support, and subsidies for transport to reach treatment centres

- ARV treatment must include access to high-quality counselling, including treatment education.

- Governments need to ensure access to second line ARV treatment, Paediatric ARV treatment and Prevention of Mother to Child Transmission services.

- Treatment for HIV co-infections such as TB and Hepatitis B and C needs to be scaled up.

The civil society consultation process proved to be a valuable lesson to show that when civil society is **asked** for their input into a regional process they will respond. Almost 600 voices in Asia have contributed to the development of the Comission's recommendations for the region. Through their responses and input civil society is calling for more engagement with governments and donors to ensure that accountability is increased at all levels of the AIDS response. Successful mechanisms, frameworks and resource allocation to engage civil society need to include civil society in all stages of development from inception to implementation. Unless all key stakeholders, including people living with HIV and marginalized populations, are included in decision-making, 'Universal Access' and other initiatives will be ineffective in reducing the impact of AIDS in Asia.

Broadening the consultation

In order to broaden and deepen the consultation with community members, it was decided to conduct a number of in-depth interviews with key informants, primarily respondents from the online survey, and to expand the scope of both the discussion points and the analysis of the replies.

In-depth interviews are formal or informal conversations with an individual about specific topics to collect in-depth, more detailed information. Participants are usually key stakeholders, community leaders or other members of a community or group.

Benifits of in-depth interviews

- Can gather rich qualitative information;
- Engages interviewees to provide honest opinions, perspectives and responses;
- Can help get new ideas and opinions;
- Can be done in any setting comfortable to the interviewee.

Disadvantages of in-depth interviews

- Reaches only a small number of people and is time intensive;
- Labour intensive data analysis is required.

Responses may highlight various issues depending on the respondent emphasis.

In-depth key-informant interviews

Based on the initial summary of the online survey, and other content from previous civil society processes (given above), an in-depth, semi-structured interview questionnaire was developed to gather rich qualitative data from key informants from different constituencies and to validate the data from the online survey. These interviews took a minimum of 30 minutes and the longest interview lasted for about three hours. In total, 85 in-depth interviews were conducted in August 2007. The questionnaire probed deeper into the four major issues emerging in the initial summary of the survey:

- Reducing HIV-related stigma
- Legal reforms that support HIV programmes and services
- Political commitment and civil society engagement in national AIDS programmes/responses
- Monitoring the response to AIDS in Asia

Key informants were identified based on online survey responses. Upon completion of the online survey, respondents had the opportunity to nominate themselves to participate as key informant interviewees and to further delve into their opinions and recommendation about the key issues identified by the survey. A team of HDN Key Correspondents[1], from the Asia region attending ICAAP in Colombo, conducted these in-depth interviews. Each in-depth interview was digitally recorded, and the responses transcribed. Some of these interviews were conducted over the phone in the lead up to the 8th ICAAP, with the majority conducted during face-to-face meetings alongside an International Treatment Preparedness Coalition (ITPC) Steering Group Meeting and at the 8th ICAAP.

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1   The Key Correspondent (KC) Team is a group of in-country writers who work in HIV and TB as well as people who are affected by and living with HIV and TB. KCs help document local HIV and TB realities, making sure that people who wouldn't ordinarily be able to tell their stories have a way to be heard. HDN coordinates and manages the KC Team.

Raising awareness at the 8th ICAAP

The 8th ICAAP meeting in Sri Lanka presented an opportunity to broaden the community consultation, based on the results of the initial online results.

In addition to conducting in-depth interviews, the HDN KC Team increased the awareness of the CAA and civil society consultation by contributing two pages of content for the daily onsite official ICAAP newspaper (4 issues). Each of the issues identified in the initial survey summary was highlighted with articles from the onsite KC team, including an interview with the Chairman of the Commission.

HDN also assisted two civil society representatives from the region in developing a civil society statement informed by the survey and in-depth interviews, which was delivered at the closing ceremony of 8th ICAAP. The statement gave an overview of their experience of the conference itself as well as called for governments and civil society to act upon the findings from the online consultation.

Civil society informing
the Report of the Commission on AIDS in Asia

The findings from the online consultation and in-depth interviews, as well as resource documentation and research about community engagement, were used to frame and develop the civil society chapter of the final commission report. A writer from the Asia region who had extensive experience working in communities within the region was contracted to work with Frika to conceptualise and write this chapter. Once drafted, the chapter saw a series of peer reviews at regional meetings and from key community stakeholders throughout the region.

The following meetings were utilized for the peer review:

- Asia Pacific Regional Civil Society Meeting on UNGASS, Chiang Mai, Thailand, September 2007
- Coalition of Asia Pacific Regional on HIV/AIDS (7 Sisters) Management Meeting, Bangkok, Thailand, September 2007

Additionally, individuals from the Australian Federation of AIDS Organisations and AusAID provided feedback to the civil society chapter.

After community review of the chapter, the draft was revised according to the inputs and submitted to the CAA to be incorporated with the rest of the report chapters.

Throughout the report writing process, Frika and the writing consultant monitored any changes and revisions that were made by the report writer to make sure that key messages of the community chapter were not weakened nor drastically changed. At the final stages of the report writing the CAA report writer incorporated the community chapter into the final report.

Sometimes the targets, for example the PMTCT program, have an ambition to reach 100% - for every woman to access the PMTCT program. But in fact less than 10% of the women in my country have access to that. "

- Mony Pen, Cambodia

Conclusions/Recommendations

The civil society consultation for the Commission on AIDS in Asia was a landmark consultation because there was such an overwhelming response from civil society, with over 600 people contributing. The consultation has shown that when asked civil society will provide genuine, informed and well thought-out input into regional priority-setting processes. The CAA civil society consultation has shown that civil society will and can contribute significantly to building the evidence base needed for informed AIDS policies and plans at the country and regional levels. Ensuring that the continuum of care and progress towards universal access to HIV prevention, care and treatment are based on the 'real' experiences of people directly affected by and living with HIV and AIDS.

The methods of conducting online surveys and in-depth key stakeholder interviews have proven to collect opinions from a broad stakeholder pool, as well as gain deeper knowledge and recommendations for an effective HIV/AIDS response in the Asia region. Online survey consultation is easily replicable for any focus issue and cost effective in consulting a wide range of stakeholders from multiple countries. Although online surveys can reach many people, self selection for responding to online surveys and limited access to the internet in some countries, continues to limit the full potential of this approach. On the other hand, respondents are more open to freely express their opinions on issues which may be controversial or 'touchy' because of the anonymity of the internet and online interface.

In-depth interviews are time and transcription labour intensive. The perception that people are not willing to give up to one hour or more of their time to talk about issues was completely unfounded in this situation. Of the people who responded to the online survey, 54 individuals indicated that they would be attending ICAAP 2008 and would be interested in being interviewed. No incentives were used to solicit responses for this component of the consultation.

Another unique component of the consultation, which helped to hold people's interest and build trust in Frika as their representative, was her commitment to reporting back and informing her constituents on the progress of the CAA. She reported the preliminary results of the survey to the whole CAA (Beijing, China, July 2007), as well as to her civil society constituents. She used the same dissemination methods to

report back as she did to enrol civil society's help in identifying HIV/AIDS priorities in the region. She also reported back to civil society on the process of the CAA prior to ICAAP 2008 and during the report launch in March 2008.

Frika's representation of civil society on the CAA was fortified by the more than 600 voices from the region. When sitting in sessions with other CAA members who were high level representatives, such as professors, politicians and epidemiologists, she experienced a great sense of confidence that she was actually representing 'real' people and that her voice was the voice of the people and not just hers in solitude.

The CAA report provided a unique opportunity to lobby for the inclusion of advocacy points and community perspectives to be included into the report. The civil society chapter and inclusion was different and significant because the community discussions and viewpoints went beyond the simplistic "include community" stage to inclusion and discussion at a high-level.

Recommendations

- Civil society consultation is necessary to ensure that policy and programming planning is representative of the needs of affected communities.

- Broad civil society participation provides valuable contributions to enhance civil society representatives' ability to represent in bodies such as the CAA, UNAIDS Programme Coordinating Board, Global Fund to fight AIDS, Tuberculosis and Malaria and UNITAID.

- Civil society consultations can be simple, effective and replicable.

- Strong civil society consultations need to be fed back to the constituent base.

- Networks are effective mechanisms for engaging a broad range of stakeholders.

- Commitment and transparency by civil society representatives in decision-making bodies further encourages civil society input.

- Civil society consultation can mobilize wider and more focused or unified civil society advocacy on priority issues on regional and country levels.

- Governments, bilaterals, multilaterals and similar agencies that are engaging civil society in consultation need to develop clear parameters of engagement and inclusion to ensure that civil society contributions are genuinely captured and utilized for making recommendations and decisions.

Looking Forward

It is clear that this publication is a first step to document what civil society consultation can achieve. The next step is to utlilise the Commission on AIDS in Asia recommendations as a door and facilitating factor for advocacy on the country level. Therefore, APN+, 7 Sisters, HDN and other community organizations will be collaborating, with support from the UNAIDS Regional Support Team Asia Pacific, on a proposed a series of activities to be carried out at the regional and country levels. These activities will increase decision makers' awareness of the Commission recommendations and build the capacity of communities to utilise the recommendations and report to support advocacy on HIV/AIDS in their countries.

Activities will include:

- Stimulating dialogue and discussions through existing regional and national online social networking platforms and mailing lists;

- Identifying and consulting country-level community advocacy "champions" to produce and implement advocacy plans at the country level with two main purposes:
  - Increase community understanding of the CAA report and recommendations at the country level;
  - To advocate with national level policy and decision makers to endorse, adopt and adapt the recommendations proposed by the CAA report.

- Following up through the monitoring of communities' understanding and use of the CAA recommendations for advocacy at the country level;

- Promoting the report and country level engagement around the recommendations at international, regional and country-level events, for example the International AIDS Conference, August 2008; 9th ICAAP, August 2009; International Harm Reduction Conference, May 2009 and other regional and national specific events.

Implementation of these activities will begin from July 2008 and peak during the 9th ICAAP in August 2009. In the lead up to this bi-annual regional meeting, communities will be consulted about how they used the CAA recommendations and how the recommendations influenced national AIDS policy making. During the conference an event will be held to launch a community progress report and report back to the larger community regarding what has been done in response to their input and perspectives.

Main highlights of the Civil Society
chapter in the CAA report[2]

■ Community participation is essential for reaching people involved in risk-associated behaviour with information and services they are likely to trust.

■ The inadequate support to capacity-building of communities restricts their meaningful participation in HIV responses.

■ Communities should nominate their own representatives to bodies like the National AIDS Commissions or Country Coordinating Mechanisms (i.e. of the Global Fund) instead of governments 'hand picking' community representatives.

■ An accountability and monitoring body, AIDSWATCH, can potentially improve transparency and accountability across sectors.

■ Responses to HIV have always relied on their success by involvement and implementation at community level but the strengths of communities and hairkey role is often undermined.

■ Without community participation and leadership, it will be difficult to influence change in the social norms that put people at risk of HIV.

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2   Commission on AIDS in Asia, Report of the Commission on AIDS in Asia: Redefining AIDS in Asia. India: Oxford University Press, 2008

- It is important to note that stigma, discrimination, gender inequality, violence against sexual minorities, and other social inequities that undermine HIV programmes, are also very localized. This underlines the need to engage local communities directly through advocacy, and indirectly through influential institutions such as faith-based organizations.

- More resources for skills training of community organizations in monitoring and evaluation of HIV programmes should be allocated. Monitoring and evaluation should also include extent and quality of civil society participation and community engagement.

- Regional monitoring of national responses can be useful for tracking countries' progress in meeting their various commitments.

- In many countries in Asia, there are laws criminalizing same sex behaviour, sex work and/or injection drug-use. There is a need for legal reforms so that supportive HIV policies can help strengthen human rights.

- Community organizations cannot participate in national processes if they lack human resources, finance, information, and preparation time. Often, they are expected to take part in processes or provide services on a volunteer basis, while covering their own transport and opportunity costs. This is unfair and ultimately counterproductive.

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CD Content
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When asked, communities answer!
We've read it for you: UNAIDS Report of the Commission on AIDS in Asia
Report of the Commission on AIDS in Asia
Asia and the Pacific Regional Consultation on Scaling up towards Universal
ICAAP 2005 Civil Society Statement
Commission on AIDS in Asia: Stakeholder consultation introduction
Commission on AIDS in Asia: Stakeholder consultation questions
In-depth interview questionnaire
CAA Civil Society Consultation – Interim Report presented by Frika Iskandar
ICAAP 2007 newspaper articles on CAA consultation themes
Tidings Issue1 Volume 1 extract
Tidings Issue1 Volume 2 extract
Tidings Issue1 Volume 3 extract
Tidings Issue1 Volume 4 extract

At the end of the day, what we have learned
is that a good AIDS response is primarily
a local response and indigenous response.
In country after country, in region after region,
we have seen it.

— Dr Anindya Chatterjee,
Program Director, HIV/AIDS
Asia Regional Program (HAARP),
AusAID