Part II

Developing policy and advocacy skills

Developing policy and advocacy skills for the involvement of affected communities in responding to HIV/AIDS
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Part 2

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Developing policy and advocacy skills for the involvement of affected communities in responding to HIV/AIDS

A publication of the Coalition of Asia Pacific Regional Networks on HIV/AIDS (the Seven Sisters)

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Chapter Credits

Part 2 of All of Us Count was written by Andy Quan. Parts of this chapter borrow from and are indebted to the work of Susie McLean.
Summary

*All of Us Count*, produced by the Coalition of Asia Pacific Regional Networks on HIV/AIDS (the Seven Sisters), aims to provide a tool which can be used to foster advocacy by communities affected by the HIV/AIDS pandemic, and to promote the involvement of affected communities in the response to HIV/AIDS at the local, national, regional and global level.

This publication is divided into two parts.

This part of the publication, Part 2:

- Describes the concepts of policy-making and advocacy and how affected communities can be engaged in this.
- Describes international and regional organisations and meetings which might provide opportunities for advocacy.

Chapter 1 of Part 2 examines the concepts of policy and advocacy and how affected communities and the Community Based Organisations (CBOs) and Non Government Organisations (NGOs) that represent them can become involved in policy-making and how they can develop their advocacy efforts. Global and regional networks on AIDS may be better placed for advocacy at this level than local organisations, and a description is given of key global networks. The chapter’s conclusion encourages organisations to consider how and where to focus efforts to influence advocacy and policy-making on the response to HIV/AIDS.

Chapter 2 introduces the Seven Sisters network and each of its members.

Chapter 3 provides a listing of regional and international opportunities for advocacy including institutions and conferences.
Chapter 1 of Part 1 describes the reasons for All of Us Count, the intended audience and the style and language used. An explanation is given of why involvement of affected communities is important as well as a description of the concept of “involvement.” Other key concepts are defined such as “community”, “affected community”, and “CBO”. The particular affected communities that are the focus of this publication are described: sex workers, men who have sex with men, injecting drug users, migrants and mobile populations, and people living with HIV/AIDS. Frameworks such as Gender, the Prevention-Care Continuum and Access to Treatment are presented. The chapter uses the example of PLWHA involvement in CBOs to explore challenges and obstacles to involvement and ends with a discussion on the challenge of defining “community.”

Chapter 2 of Part 1 provides a principle framework for All of Us Count, that of a human rights approach to HIV/AIDS. After defining the concepts of human rights in relation to HIV/AIDS, the question of what constitutes an effective response to HIV/AIDS is explored. The chapter looks at human rights issues pertaining to AIDS and to the affected communities such as People Living with HIV / AIDS (PLWHAs), sex workers, Men Who Have Sex With Men (MSM), and Injecting Drug Users (IDU). This discussion of human rights and HIV/AIDS also looks at non-discrimination, testing, confidentiality, and criminal and public health laws.

Chapter 3 of Part 1 introduces the concept of a case study and discusses how it will be used in All of Us Count. Examples of how organisations involve affected communities are given in ten case studies which also includes discussions of mobilisation, capacity-building and community development. The chapter’s conclusion draws together key lessons from the case studies which can be used for mobilising community organisations, advocating for the involvement of affected communities, and involving affected communities in our own organisations. It also asks questions to encourage organisations to reflect on how they can improve their response to HIV/AIDS and their involvement in a broader response.
Introduction

Because we assume that most readers of All of Us Count work in the field of AIDS, it is possibly unnecessary to note the following: The latest UNAIDS estimates from 2002 report that 42 million people in the world are living with HIV/AIDS, of which 7.4 million live in the Asia-Pacific region. Since the epidemic started, approximately 28 million people have died. AIDS is affecting the very development of nations - slowing economies, harming food production and education by killing farmers and school-teachers, and changing the entire demographic of national populations as countries lose adults in their most productive years of life. Most people in the world do not have access to life-saving medicines and will die.

On the other hand, it is possibly very useful to note the statistics above because it is why we are working in the field of AIDS and why this publication is being written - so that we can try to do something about it. It may also be useful to motivate ourselves and give us inspiration - and it may be useful for our advocacy work - to remind those who are ignoring AIDS or moving too slowly that this is not a problem of mathematics or logic but of human lives lost.

The specific reason for All of Us Count is that 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. However, this principle is not universally observed. Many governments and programs operate without involving or consulting with affected communities. A “top-down approach” means that those with power - government officials, medical officers, bureaucrats - impose decisions and proposed solutions upon communities. In order to counter this, we need arguments and evidence that support a response to HIV/AIDS that involves community, the grass-roots level, and people who are living with as well as those who are affected by HIV/AIDS.

Many NGOs and CBOs are weak - they have more work than their small staff can handle, and limited resources. NGOs and CBOs that work with affected communities can be especially strained because of the complications and difficulties of working with groups that face discrimination and marginalisation. NGOs and CBOs that work under these conditions often do not have the resources to develop their work in the areas of policy and advocacy. Most energy is put into keeping the organisation alive, serving their communities and responding to other issues.

Few publications specifically focus on the involvement of affected communities in responding to HIV/AIDS and the development of policy and advocacy skills by CBOs and NGOs. All of Us Count aims to address these two important issues.

In Part 1 of All of Us Count, we presented reasons for why affected communities should be involved in responses to HIV and AIDS. We presented a human rights framework which provides the basis for the mobilization of affected communities which would allow their involvement in responses to HIV and AIDS. Case studies were given of how affected communities became involved in different organisations, how organisations engaged in effective advocacy on HIV/AIDS issues, and how programs became more effective through the involvement of affected communities.

Part 2 of All of Us Count looks at policy, advocacy, and how affected communities can maximize their involvement in global, national and local policymaking.
Chapter 1 How affected communities can maximize their involvement in global, national and local policymaking.

Introduction

In this chapter, we will look at how affected communities can maximize their involvement in global, national and local policymaking. But before we do this, it is useful first to examine the concepts of policy, policymaking and advocacy.

What is Policy?¹

Policy is a complicated concept to describe. Often, people think of policy as a finished product, a set of guidelines or rules, a statement of belief, or a set of opinions formulated into an official document. For example, an organisation developing a policy on HIV vaccines might look at a broad range of areas to define issues which they may have not been considered before, or considered in a formal way.

Policy is often used as an advocacy tool, as it may aim to define an issue in a way such that it can be used for lobbying purposes. For example, a policy on HIV and human rights written by a CBO might be used to lobby a government to adopt a similar policy, or to point out an action of the government that might be in contradiction of the policy.

However, policy is not only about the finished product. It can also refer to the process, the range of steps taken in order to act on an issue. While the culmination of these steps may be getting something defined or changed, policy can also be defined as the process preceding this. In its broadest sense, much of the work of NGOs and CBOs could be described as policy development simply because it can mean identifying what we believe and then acting upon it.

Seen in this way, the ways in which affected communities can maximize their involvement in global, national and local policymaking are numerous. The process may be an internal one where communities develop a set of policies that can be used to lobby others, i.e. other organisations, the government, and regional bodies. CBOs would be seen as taking a lead role. Or the process may involve an extensive collaboration by which communities and the CBOs that represent them develop policy working with other parties. Or the process may be less involved where CBOs feed into and support the process of policy-making by other parties.

The central aspects of policy include consultation, identification, decision-making and action. At any of these stages of policy-making, CBOs can play a lead, collaborative, or supportive role.

Is it also useful to see policy as a process of development and education. When we see policy as process and not only as a product, we can see how policy can act as an educative process, bringing a set of ideas from an organisation or group of people along a path towards a clearer definition. From this process of definition and debate comes a set of plans for action or response, followed by the action or response itself. So, involvement in policymaking is not only about end results but about being part of a process. In this scenario, positive outcomes may result in the future rather than immediately. For example, a local sex worker organisation may not achieve changes in city by-laws and zonings during a first round of meetings, but they may establish the precedent for their continued participation in discussions on the issue.

¹ This section draws generously from “WHAT IS POLICY? Describing the Policy Development Process” by Susie McLean, Australian Federation of AIDS Organisations (AFAO), 1996.
It is also recommended that efforts be made to affect the nature of the policy-making process itself. Policy-making that takes into account the views and experiences of affected communities is likely to be of a different nature than policy-making by a handful of individuals locked away in a meeting room working on a document. Affected communities, as represented by CBOs and NGOs, should promote a process of policymaking that encourages people involved to sharpen their views, become better informed and become more involved in planning how they will respond. It is a process that builds support, expertise and commitment along the way, rather than asking for it after a product has been finalized.

Another consideration in the policy process is implementation. Policy documents should be developed with a plan for implementation and an understanding of the complexities of implementation: the work of making your set of beliefs ‘live’ - testing them out in the world, convincing governments and constituents and the public of the value of these beliefs and changing the environment accordingly.

It is important to mention here that not all policy work involves all these aspects to the same degree. Different contexts and situations require different processes, but it is useful to decide how you will proceed, mindful of the fuller dimensions of the policy development process.

Policy development can also be seen as a process of political activity, for negotiating change or lobbying, or the end stage of a research process.

Policy can respond to current situations that ‘happen’ in the world, or alternatively, policy can prompt a process of change. Examples of these two situations include a government deciding to review its HIV testing guidelines in the light of home testing kits becoming available, and we decide we have to be part of the process of consultation and develop policy accordingly.

Or alternatively, we might think that it is important to develop a maternity leave policy within an organisation simply because it is a good idea.

In summary, the involvement of affected communities in policy-making could occur at many levels. It is useful to keep a broad definition of policy, and to remember that it includes the process itself of policy-making as well as actions that might result from it. At the same time, we need to be specific about how we want to be involved in policy-making even though this will vary between situation and context.
What is Advocacy?

If we are to examine how affected communities can be involved in policy-making, it is necessary to also examine the concept of advocacy. Policy-making and advocacy are often linked, because the aim of much policy is to achieve change in an influential way. Action-driven policy will therefore require advocates to use it to achieve policy.

CBOs, NGOs and the communities they represent will need to be familiar with advocacy for various reasons. As affected communities are too often left out or excluded from the response to HIV, we need to “advocate” for full and meaningful participation. However, in order to participate, we must be able to offer a certain level of expertise and familiarity with policy and advocacy issues. If we press to be involved in formulating a policy document for increased leadership on HIV/AIDS issues, we, ourselves, will need to know why we want increased leadership, what kind of leadership we want to see and how we can advocate for that outcome.

But what is advocacy? Many organisations have their own definitions. The following is a definition from UNICEF

Advocacy: Organizing information into arguments to be communicated through various interpersonal and media channels, with a view to getting political and social leaders’ acceptance, and preparing a society for a particular development program

Others emphasize the “action” part of advocacy as in “a series of actions designed to persuade and influence.” The International HIV/AIDS Alliance (The Alliance) emphasizes the idea that advocacy is persuasion directed at influential people rather than aimed at the general public or specific groups of people. This type of persuasion might be more about education or community mobilization.

Considering the above, the basic aims of advocacy could include any of the following:

• To change an existing situation
• To improve the quality of life of less powerful and more vulnerable groups
• To persuade people to accept change
• To introduce a new law or policy
• To ensure that a law or policy is enforced
• To change the attitude or behaviour of a group of people

This can be done through any of the following means:

• Talking to individuals
• Talking to groups
• Using the media
• Joining coalitions
• Managing information
• Policy-making
A definition for an “advocate” might be: “someone who works to raise awareness and gain support for a cause.”

However, as the Alliance points out, there are no internationally agreed upon definitions of advocacy and it is not necessary to agree on all the issues raised. Furthermore, local definitions may be lacking. A study on advocacy in Cambodia noted: “A few years ago there was no term in Khmer to describe the concept of advocacy.”

**Advocacy Resources**

The sections above are only meant as an introduction to the concept of advocacy. Other organisations have written guides specifically aimed at supporting NGOs and CBOs in using advocacy in HIV/AIDS, and general guides on advocacy are also available.

Toolkits such as that produced by the Alliance are recommended for organisations to build a working definition and agreed understanding of “advocacy” which can then be used towards the key goals of this publication, ensuring and increasing the role of affected communities in the response to HIV/AIDS policy-making.

We highly recommend Advocacy in Action - A Toolkit to Support NGOs and CBOs Responding to HIV/AIDS produced by the International HIV/AIDS Alliance. Published in July 2002, this toolkit builds on initial experience gained though skills-building workshops in Burkina Faso and the Philippines during 1999. It aims to help NGOs/CBOs to reflect on what advocacy work suits their organisations, to plan their advocacy work and build specific advocacy skills.

It is clearly and comprehensively written and can be used by CBOs and NGOs to implement training within their organisations.

It is available at:

http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Toolkits/Advocacy_Toolkit_Complete.pdf

The Alliance’s website (www.aidsalliance.org) also contains guides on advocacy specifically relating to gender and reproductive health.

Here are other references for advocacy materials:


This search engine on the web includes a specific section on HIV/AIDS advocacy that includes the web addresses for various advocacy organisations.

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2. The International Planned Parenthood Foundation have produced an Advocacy Guide on HIV/AIDS which is available at:

http://www.ippf.org/hivaids/advocacyguide/index.htm

This guide compiled by the International Planned Parenthood Federation provides information on topics such as:

- The purpose of HIV/AIDS advocacy;
- Advocating for different groups of people that are at higher risk of contracting HIV;
- Promoting male and female condoms;
- HIV in the workplace.

Examples of best practices are included in the report, as are useful publications and internet resources.


It is available at: http://www.communitychange.org/Publications/CCCNews17.pdf

Individual articles from this publication are available at: http://www.communitychange.org/advocacy.htm

4. Courses on advocacy aimed at those in NGOs and CBOs are occasionally offered. An example of the type of course that may be available is:

Advocacy and Networking (Nov 10-28 2003)
Location: Antigonish, N.S., Canada
Event Details: The Certificate in Advocacy and Networking will focus on advocacy directed at changing the policies, positions or programs of any type of institution. This includes a small NGO, a council of elders, a multinational corporation, a government ministry, a nation state, an international agency or other institutions.

This 3-week programme is intended for those having some direct experience in advocacy work and wanting to enhance their understanding and skills in this area. Bursary support may be available to organisations in the global South.

Website: http://www.stfx.ca/institutes/coady/ie_index.html - then click on “Our Programs, Educational, Certificate Programs, Certificate in Advocacy and Networking.”

If you think courses like this may help you or your organisation with your work, it might be useful to do regular searches on the internet inputting words like: advocacy, courses, programme, and scholarship into search engines like www.google.com.
Becoming Involved in Policy-Making

How do we become involved in policy-making? First of all, in order for affected communities to become involved in policymaking at various levels, there needs to be individuals or organisations who are willing and able to do this on behalf of these communities. They need to have the capacity to negotiate and collaborate with other parties. There also needs to be the willingness on behalf of policy-makers to involve affected communities.

CBOs, NGOs and individuals working on behalf of affected communities must have a clear understanding of their communities - their needs, their political aims, how, where and why they operate. They will also need to have a process of consultation to ensure that those needs are accurately reflected over time. In complicated negotiations, it will also be necessary to know what core values are being promoted, and in terms of a number of needs and desires, a prioritisation of which are the most important.

An audit of the abilities and resources of these organisations and individuals is also necessary. Are time and resources available to be able to attend particular meetings or take part in a series of consultations?

What kind of organisation you are may also influence your ability to affect change and participate in policy-making. A police station may respond better to an organisation that is located locally and close to them. On the other hand, the authority of a national organisation may be useful. Or, if the police station is likely to be influenced by the idea of regional or international attention, organisations that work on that level may also be of some use. At national meetings, peak-body organisations\(^1\) may be the only type of organisation able to speak. This may also apply to thematic areas. For example, the International Council of Women living with HIV/AIDS (ICW+\(^1\)) may be able to effectively put viewpoints across in a regional forum dedicated to gender and women's issues, whereas the Global Network of People living with HIV/AIDS (GNP+) may not.

Just as important is an understanding of what opportunities are available. What institutions have the greatest influence on these communities? Which institutions could affect the greatest change? What meetings are taking place, and how does one become involved? How can themes of certain meetings be used to promote areas of concern for affected communities?

Each affected group may have slightly different issues to advocate depending on what institution or meeting is being approached, and at what level the group is operating on - local, national, regional or international. Your organisation might want to advocate on the same issue with many different organisations (for example, the wide promotion of the principle of Greater Involvement of People Living with HIV/AIDS). Or you may want to promote multiple issues within the same institution (for example, within your national body that deals with HIV/AIDS, pressing for different issues such as better consultations with affected communities, designated seats on committees for representatives from affected communities, and improving treatment access initiatives).

\(^1\) A National organisation that represents other member organisations.
Other examples of kinds of advocacy:

- On the local level, a group working with men who have sex with men might want to work with police to ensure that they do not interfere with outreach education to men who have sex with men in public places like parks. On a national level, the group might want to lobby their national governments to decriminalize homosexuality, or to ensure that anti-discrimination measures are in place.
- The advocacy needs of a migrant woman with HIV would be quite different. She might need access to basic healthcare if she does not have legal status in the country she is working in. Or she might need information about HIV/AIDS in her own language. She might need financial support. Attention might be needed to how her gender increases her vulnerability to becoming ill, or affects her access to services.
- International or regional organisations may need lobbying to take issues seriously. For example, the European branch of the International Lesbian and Gay Association has had great success in recent years with the European Union and the Council of Europe in recognising lesbian and gay rights.

These are only a few examples. You and your organisation will need to determine what your advocacy needs are, and then what influential institutions need to be lobbied.

Examples of local institutions that may be involved in policy-making related to HIV/AIDS and affected communities are:

- City councils, neighbourhood councils, local hospitals, police stations, local NGOs and CBOs, business organisations, chambers of commerce, local media such as radio, TV and internet services, local religious institutions, schools and universities.

Examples of national institutions that may be involved in policy-making related to HIV/AIDS and affected communities are:


Examples of regional institutions that may be involved in policy-making related to HIV/AIDS and affected communities are:

- Regional conferences on HIV/AIDS, regional political groupings such as ASEAN, regional bodies of UN bodies such as UNESCAP, regional banks such as the Asian Development Bank. Regional business councils, trade networks, NGOs and CBOs, media organisations, educational organisations, church and faith-based organisations.
Examples of international institutions that may be involved in policy-making related to HIV/AIDS and affected communities are:

- Global institutions such as the World Bank, the World Health Organisation, UNAIDS, other UN bodies, World conferences on HIV/AIDS, International NGOs and CBOs and networks, the International Labour Organisation.

**Regional and Global Networks on HIV/AIDS**

For CBOs and NGOs that work on the local level, it may seem a daunting task to try to engage with advocacy and lobby work on a regional or international level. One way to do this is to become familiar with organisations and networks that work at this level. When you have made contact with them and established a relationship, you can put forward your concerns either by asking them to do it on your behalf, or by becoming involved in the organisation and becoming part of that advocacy work.

One definition of a network is: An extended group of people with similar interests or concerns who interact and remain in informal contact for mutual assistance or support. Networks for HIV/AIDS involve both informal ways for individuals and organisations to work together - through personal relationships, e-mails, meetings - and formal ways - meetings, newsletters, and governance structures.

To become involved with a network can be easy or difficult. Many networks are informal, and simply by getting in contact with them, you can be considered a member. On the other hand, many regional and international networks are poorly resourced. They may be struggling for funds, and have only one or two staff members. So, if those people are busy, they might not be able to respond to you. If you wish to become involved with a regional or international organisation, it helps to think about the following:

- Why do you want to become involved?
- What can the organisation help you accomplish?
- Is that within the mandate of the organisation? Is it a reasonable request?
- What can you offer the network?

In order to work effectively with networks, or in fact with any organisation, it is good to be specific. For example, rather than "this network can help build our capacity", you would need to be able to identify a capacity-building project that the network is involved in that you can participate in.

On the global level, there are a small number of international networks for CBOs and NGOs. The main ones are the International Council of AIDS Service Organisations (ICASO), the Global Network for People Living with HIV/AIDS and the International Council of Women living with HIV/AIDS.
ICASO is the International Council of AIDS Service Organisations, a global network of non-governmental and community-based organisations. ICASO was formed in 1992 and is the only central secretariat based in Canada. ICASO is a non-governmental organisation accredited to the United Nations Economic and Social Council (ECOSOC). ICASO’s key mission is to mobilize and represent CBOs, build capacity of CBOs and NGOs to respond to HIV/AIDS and to promote Human Rights and GIPA. ICASO plays a major role at the International AIDS Conferences, and do important work at global and regional forums representing the interests of communities.

The Global Network of People Living with HIV/AIDS (GNP+) is a global network for and by people with HIV/AIDS. The central secretariat of the network is based in Amsterdam, Netherlands and has a board of 12 members representing the various international regions. The overall aim of GNP+ is to work to improve the quality of life of people living with HIV/AIDS. This is achieved by helping to build the capacity of people with HIV/AIDS on the global, regional and national level. Like ICASO, GNP+ plays an important role in international and regional conferences, representing and promoting the interests of positive people. They also host an international annual conference.

The International Community of Women Living with HIV/AIDS (ICW) was founded in 1992 and is the only international network run for and by HIV positive women. ICW was founded in response to the desperate lack of support, information and services available to women living with HIV worldwide and the need for these women to have influence and input on policy development. ICW’s overall goal is to improve the lives of women with HIV and AIDS throughout the world. They have two staff, many volunteers and work with 15 key contacts around the world. They sponsor workshops, do trainings, produce a newsletter and also play a representative role at international and regional conferences.

Depending on your interests, locations and networks, you may end up taking part in a project or workshop sponsored by one of these networks, or meet one of their representatives at an international or regional meeting. They most often work through local representatives, and the best way to make contact or become involved would be through your local networks. ICASO’s Asia-Pacific representative is the Asia Pacific Council of AIDS Service Organisations (APCASO) and GNP’s is the Asia Pacific Network of People Living with HIV/AIDS (APN+). ICW has Asian and Pacific representatives. Whether global or regional, these organisations have relatively little resources and it is important not to place too great an emphasis on their representative role. While they do their best to represent the interests of their constituencies, if you have not heard of them, or are not in contact, it does not mean that they ineffective at their work. If you have comments, criticisms, or offers of support, you might want to investigate more about them and try to understand first how they operate.

**Websites:**

ICASO:  http://www.icaso.org  
GNP+:  http://www.gnpplus.net/  
ICW+:  http://www.icw.org/index.html
In the Asia-Pacific region, **The Coalition of Asia Pacific Regional Networks on HIV/AIDS (the Seven Sisters)**
is a broad-based alliance bringing together seven regional networks: the AIDS Society of Asia Pacific (ASAP), the Asia Pacific Council of AIDS Service Organisations (APCASO), the Asia Pacific Network of People Living with HIV/AIDS (APN+), the Asia Pacific Network of Sex Workers (APNSW), Asia Pacific Rainbow (APR), the Asian Harm Reduction Network (AHRN), and Co-ordination of Action Research on AIDS and Mobility in Asia (CARAM Asia).

More information about the Seven Sisters is found in Chapter 2.

All of these organisations and networks promote the involvement of affected communities in policymaking at global, regional national and local levels. Publications like this one, or other advocacy documents or tools from these organisations may help you with your advocacy work to promote your involvement in policymaking. At the same time, you might be able to identify ways that your organisation can help these networks in advocating for this goal.

You and your organisation may also be interested in doing advocacy with particular regional and international institutions or meetings. A description of these as well as case-studies of advocacy work with them is included in Chapter 3.

**Interconnection: links between different levels of advocacy**

The boundaries between what is considered “international” and “local” have become increasingly blurred in the last decades. The involvement in policymaking by affected communities can take place on many levels, and can have consequences on other levels. There are also many ways in which we can work, advocate and be represented.

In general, it is best to consider what level you are working on, and how that relates to other organisations. Most community-based organisations work on the local level. How can these organisations be involved on a national level or beyond? You may work through a federation or a national organisation that represents the issues that you are also working on - either by asking them to work on your behalf, or by actively working as part of that organisation. National organisations will have the same considerations. Are there regional and international bodies that can represent their interests, or is there ways that they can be active through these organisations?

The International Council of AIDS Service Organisations is an example of this model. ICASO works primarily at the international level as a sponsor of the International AIDS Conference and focusing on global advocacy and policy-making. But they also work with regional CASOs in North America, the Asia-Pacific, Africa, and Latin America and the Caribbean. These regional bodies carry out regional advocacy, policy-making and projects. But in order to do this, they work closely with member organisations, who may be national organisations or federations, or may focus more on local issues. All levels of policy-making can affect each other. The concerns of a sex worker organisation in Malaysia might be adopted as a key advocacy item by ICASO. A publication by ICASO might be used by a local drug user agency in Nepal to lobby local officials.

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4 Again, see Altman’s Global Sex (2001), in particular Chapter Two: The Many Faces of Globalization
Furthermore, national, regional and international organisations and meetings need to reflect the needs of each affected community and individual, and therefore, local organisations should at times participate in these forums. However, mechanisms may need to be put in place to ensure that participation is authentic - translation and interpretation, background materials for meetings, and if necessary, skills-building and resources.

**Conclusions**

This chapter aimed to explore how affected communities can become involved in policymaking at local, national, regional and global levels. It first explained the concept of policy noting that policy is not only a finished product but the process of arriving at a position or set of ideas. Policy is also linked to advocacy, and an introduction to this concept was also given. Advocacy aims for social and political changes by lobbying and working with influential people. An explanation followed of how your organisation might participate in advocacy, what kinds of advocacy might be undertaken, and what types of institutions might be targeted. A description of regional and global networks on HIV/AIDS was given. Reference was also made to Chapter 3 that describes international and regional bodies for affected communities becoming involved in policymaking. These range from meetings such as the regional ICAAP to global bodies such as UNAIDS.

The chapters of Part 2 of *All of Us Count* are intended to stimulate questions for you and your organisation, such as:

- **Why do we need to be involved in policymaking?**
- **At what level - municipal, national, regional or international - can we best operate?**
- **At what levels, can we effectively lobby?**
- **Which meetings or institutions should we work with?**
- **Which meetings or institutions are easiest to work with?**
- **What key issues do we want to build policy on?**
- **Are other organisations or individuals seeking to work in the same area?**

At a meeting in Canberra on access to treatment in 2002, the International Roundtable, participants agreed on a framework for moving forward. The last point in this framework was “Don’t wait. Start now. Learn by doing.” This does not mean to act rashly - to move ahead without doing effective preparation - preparation which could include building alliances with others, studying and learning about the issue, or finding out what others have done in similar circumstances. In the context of the Roundtable, what it meant was that the issue of access to treatment is of such crucial importance that we have to act immediately and that we possess enough knowledge and expertise to move forward without delay.

In the same way, the involvement of affected communities in a response to HIV and AIDS, which includes policymaking at all levels, is integral. If it is not happening, it should, and quickly. For this issue too, we have the knowledge and expertise to move forward without delay, and we can learn at the same time during this process to become more effective at what we do.
Chapter 2

Introduction to the Seven Sisters

In the Asia-Pacific region, The Coalition of Asia Pacific Regional Networks on HIV/AIDS (the Seven Sisters) is a broad-based alliance bringing together seven regional networks: the AIDS Society of Asia Pacific (ASAP), the Asia Pacific Council of AIDS Service Organisations (APCASO), the Asia Pacific Network of People Living with HIV/AIDS (APN+), the Asia Pacific Network of Sex Workers (APNSW), Asia Pacific Rainbow (APR), the Asian Harm Reduction Network (AHRN), and Co-ordination of Action Research on AIDS and Mobility in Asia (CARAM Asia).

Discussions between networks were initiated during the 5th International Congress on AIDS in Asia and the Pacific (ICAAP) in Kuala Lumpur in 1999. After 18 months of dialogue the Coalition was formalised in February 2001 at Kuala Lumpur.

These networks have experience and expertise in initiating and implementing programmes dealing with affected communities and vulnerable populations such as drug users, sex workers, transgender communities, men who have sex with men (MSM), HIV+ people and mobile populations. Together, they have established a secretariat and are currently working on two major projects - on Gender and Sexuality, and on the Greater Involvement of People Living with HIV/AIDS (GIPA). They also produce publications, and meet regularly to ensure that the networks are up-to-date on each other’s work.

The Asian Harm Reduction Network (AHRN) is a unique project, a global information and support network, created to link and support the people and programmes working in Asia to stop HIV among injecting drug users. Hundreds of individuals and organisations participate in the network and AHRN is endorsed by UNAIDS, the World Health Organisation (WHO) and many governments who see harm reduction and networking as key approaches in the fight against HIV/AIDS. Their main goal is to promote activities for preventing HIV and other harms associated with drug injecting. They are involved in advocacy, training, information sharing and networking.

Asia Pacific Network of Lesbians, Gays, Bisexuals & Transgenders (AP Rainbow) started as an e-mail-list following a meeting of lesbian, gay, bisexual and transgender delegates at the 5th International Congress on AIDS in Asia-Pacific (ICAAP) in 1999 in Kuala Lumpur, Malaysia. The previous ICAAPs in New Delhi, Chiang Mai and Manila hosted a few gatherings which were instrumental in bringing people together to share experiences, discuss issues and plan some actions around sexuality and gender-related issues. They had their first General Assembly at the 6th ICAAP in Melbourne and have since had a Strategic Planning Workshop. They aim to become a more formalized network.

The AIDS Society of Asia and the Pacific (ASAP) is an independent, non-governmental body of experts from Asia and the Pacific committed to reducing the transmission and impact of HIV/AIDS. It was born out of the first regional conference in Canberra in August 1990. Since then the primary role of ASAP has been to ensure the continuation of regional conferences, the next of which will possibly be held in Kobe in 2005. ASAP will continue to be the major sponsor of ICAAPs, along with UNAIDS, and welcomes other regional networks as co-sponsors. With a staff of one, they are seeking to collaborate with other partners, in order to work in a number of priority areas that they have identified including Prevention, Treatment, Care and Support, and Women, Gender and HIV.
The Asia Pacific Council of AIDS Service Organisations (APCASO) is a network of non-governmental and community-based organisations that provide HIV/AIDS services within the Asia Pacific region. APCASO is part of the International Council of AIDS Service Organisations (ICASO). With a secretariat in Malaysia, APCASO focuses on capacity-building, networking and advocacy. Key concerns and focuses for programmes are human rights and discrimination, UNGASS and the Global Fund. APCASO currently acts as the secretariat for the Seven Sisters.

The Asia Pacific Network of People Living with HIV/AIDS (APN+) is committed to improving the quality of life of people with HIV/AIDS in the region. It was born in February 1994 when 42 people living with HIV/AIDS (PWHA) from eight different countries met in Kuala Lumpur, Malaysia to lobby for the betterment of PWHA in the Asia Pacific region. Today APN+ has become a regional network of GNP+ (Global Network of People Living with HIV/AIDS) with contacts and representatives in over 23 countries and a secretariat in Bangkok. APN+ has working groups on Information Exchange; Human Rights; Skills Building; and Access to Treatments as well as a steering committee.

Co-ordination of Action Research on AIDS and Mobility in Asia (CARAM Asia) is an initiative of NGOs involved in migration issues in Asia. These NGOs were concerned about the increased vulnerability of migrants in terms of health in general and STD/HIV/AIDS infection especially. Simultaneously, the HIV pandemic has special consequences for the human rights of migrants that have to be addressed. They focus on participatory action research initiatives on AIDS and mobility, community-based interventions, advocacy, and work to develop a regional network across Asia in partnership with other networks and agencies. Their secretariat is located in Malaysia.

The Asia Pacific Network of Sex Workers (APNSW) is an informal network of sex workers and support organisations for sex workers in the Asia & Pacific Region. Since 1995, two regional meetings were held to facilitate networking among sex workers and the groups that support them. The first one was a symposium, “Creating an Asia and Pacific Network of Sex Workers”, which was held during the 3rd International Conference on AIDS in Asia and the Pacific (ICAAP) in Chiang Mai, Thailand in 1995. The second meeting was a workshop that took place during the 4th ICAAP in Manila, Philippines in 1997. During the 5th ICAAP in Kuala Lumpur in 1999, an informal meeting was organised. The network operates primarily as a listserv of community but they are also in their final stage of producing a manual entitled “Making Sex Work Safe in Asia & the Pacific.”

More information about the Seven Sisters and each of its members can be found at the website: www.7sisters.org.
Chapter 3  Regional and International Opportunities and Case-Studies

Introduction

Regional and International Opportunities and Case-Studies

This chapter will describe a number of international and regional opportunities for the involvement of affected communities in policy-making. Short descriptions of each will be given which include information about the event or project, and what kind of policy-making opportunities exist. While many of these items are specific events that have taken place or will take place, they are aimed to give a general idea of what types of advocacy opportunities exist.

Institutions

The United Nations and UNGASS

The United Nations has addressed HIV and AIDS through a number of its institutions (such as mentioned below). However, its most important commitment was through the Declaration of Commitment on HIV/AIDS (The Declaration) which was made by governments from 189 countries at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001. UNGASS itself presented an important opportunity for civil society to advocate for the inclusion of affected communities in responding to HIV and AIDS. Only a few civil society representatives played key roles in their country representations yet many organisations gathered at the same time to lobby for a Declaration that reflected key principles of community inclusion. This was a success and a failure. The Declaration states a need to recognize and include affected communities but fails to mention some of them by name, for example, men who have sex with men.

As of April 2003, much more attention globally is being placed on the Global Fund rather than UNGASS, but UNGASS is a powerful advocacy tool which could be used by affected communities. Countries are required to do an annual report where they compare the progress of their response to AIDS with the indicators stated in the Declaration that aim for improved responses to AIDS. Civil society should be a part of the reporting process, and they can use this process as a way to develop stronger working relationships with national bodies.

Case Study - UNGASS Module: The first workshop on using UNGASS for an advocacy tool at the national level was held in October 2002 in Manila. Over 20 participants from NGOs and CBOs were present. Presentations included overviews of UNGASS, UNGASS indicators, and how to compare them to the national strategy on HIV and AIDS. The Seven Sisters strongly recommends that you do one of these workshops if possible. A full write-up on the module used to run the workshop is available at www.apcaso.org.
The United Nations Joint Programme on HIV / AIDS (UNAIDS)

The United Nations recognized by the mid-1990s that no single United Nations organisation could provide the needed coordinated response to HIV/AIDS. Responsibility was moved from the World Health Organisation to a newly created entity, the Joint United Nations Programme on HIV/AIDS (UNAIDS). This joint and cosponsored programme drew together six original Cosponsors of UNAIDS—the United Nations Children’s Fund (UNICEF); the United Nations Development Programme (UNDP); the United Nations Population Fund (UNFPA); the United Nations Educational, Scientific and Cultural Organisation (UNESCO); the World Health Organisation (WHO); and the World Bank— who were joined by the United Nations International Drug Control Programme (UNDCP) in April 1999 and by the International Labour Organisation (ILO) in October 2001.

The goal of UNAIDS is to catalyse, strengthen and orchestrate the unique expertise, resources, and networks of influence that each of these organisations offers. Working together through UNAIDS, the Cosponsors expand their outreach through strategic alliances with other United Nations agencies, national governments, corporations, media, religious organisations, community-based groups, regional and country networks of people living with HIV/AIDS, and other nongovernmental organisations.

UNAIDS offers many resources useful for HIV/AIDS advocacy ranging from country profiles to their Best Practice Collection. More importantly, their policy documents and approaches support the principles discussed in this publication: the involvement of affected communities, capacity-building, the greater involvement of PLWHA, and the promotion of partnership between sectors.

The Global Fund for AIDS, Tuberculosis and Malaria (Global Fund)

The Global Fund for AIDS, Tuberculosis and Malaria (Global Fund) was formed to increase global funding to enhance the response to HIV/AIDS, Tuberculosis and Malaria. It has become a critical player in the fight against AIDS. It aims to provide funds to countries who make applications through their “Country Coordinating Mechanism” or CCM. It is of critical importance that civil society and affected communities be included in all levels of decision-making concerning the Fund. At the board level, this is done through positions representing NGOs in the North and South and affected communities.

At the country level, Global Fund processes offer an unprecedented opportunity for the involvement of civil society as the Fund requires applications to demonstrate the inclusion of affected communities. The process of preparing national applications requires the development of national strategies for HIV/AIDS, multisectoral strategies, and financial and strategic planning. Affected communities need to be involved in this to ensure our continued involvement, as well, that our concerns and needs are represented. Many national CCMs have shown a poor performance thus far on including civil society and PLWHA. An ongoing process of advocacy is needed for our inclusion.

Furthermore, the process of applications also gives the opportunity for advocacy on increasing access to treatment, as recommended by a number of Global Fund activists, who are pushing for the inclusion of strong
treatment components in country applications.

Case-Study - keeping CCMs accountable: The World Health Organisation regional offices organised “informal meetings” in various regions for “information sharing on the Global Fund to fight AIDS, TB and Malaria” following the Barcelona World AIDS Conference. However, they neglected to involve NGOs and CBOs in the meetings. A previous meeting in Beijing in February 2002 also neglected to involve civil society. ICASO and APCASO protested the omission of civil society at the Asian meeting and after negotiations with UNAIDS and WHO, UNAIDS agreed to sponsor a meeting similar to the one described above focusing on key NGO representatives. The meeting successfully took place in Bangkok bringing together over thirty-five participants from thirteen countries to assess civil society participation in the Fund. Ongoing assessment of the Fund is continuing.

The World Health Organisation (WHO)

The World Health Organisation is the United Nations specialized agency for health. It managed HIV/AIDS issues until UNAIDS was established. WHO is governed by 192 Member States through the World Health Assembly. The Health Assembly is composed of representatives from WHO’s Member States. The main tasks of the World Health Assembly are to approve the WHO programme and the budget for the following biennium and to decide major policy questions. This Assembly is an important forum for AIDS and other related issues. WHO has regional offices around the world, and is involved in many activities related to AIDS. They see themselves primarily as providing assistance for technical support and project implementation. At the same time, their website states that their new Corporate Strategy “calls for building new partnerships, developing creative ways of networking and exploring new avenues for action” in terms of working with civil society.

Case-Study - inclusion of community: In May 2003, two regional offices of WHO organised the Bi-regional Meeting on Scaling-up HIV/AIDS Care Including Antiretroviral Treatment. With approximately fifty participants expected, the regional offices WHO had only specifically invited one community/PLWHA representative (others were dependant on invitations through country delegations.) APCASO working with the Australian Federation of AIDS Organisations (AFAO) felt that this was insufficient and would not reflect a commitment to partnership with civil society nor representation of affected communities. The two organisations lobbied WHO for greater inclusion of community and eventually, invitations were extended to six more civil society representatives.

United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP)

The regional arm of the United Nations Secretariat for the Asian and Pacific region is the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP). It has a secretariat in Bangkok. The main legislative organ of UNESCAP is the Commission, which meets annually at the ministerial level and reports to the UN’s Economic and Social Council (ECOSOC). It provides a forum for all Governments of the region to review and discuss economic and social issues and to strengthen regional cooperation. The Advisory Committee of Permanent Representatives and other Representatives Designated by Members of the Commission (ACPR), composed of UNESCAP members and associate members, meets almost every month to advise and exchange views with the Executive Secretary on the Commission’s work. Any of their sub-components - on Social Development, Population and Rural and Urban Development, or Development Research and Policy Analysis - could take a stronger interest in HIV/AIDS.

Opportunely, the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) adopted as the theme topic for the fifty-ninth session (scheduled for April 2003, but postponed to September) “Integrating
economic and social concerns, especially HIV/AIDS, to meet the needs of the region.” The meeting should involve representatives from civil society, and any follow-up items from this session should also involve NGOs and CBOs.

A 2003 publication has been produced for this session called “HIV/AIDS Prevention, Care and Support: Stories from the Community” which has similar case studies to the ones included in Chapter 2. It includes community responses to prevention focusing on youth, mobile populations, men who have sex with men, sex workers, and injecting drug users. Stories come from Vanuatu, Tonga, Cambodia, Philippines, Japan, China, Uzbekistan, India, Bangladesh, Australia, and Pakistan. Case studies are also given on community responses to care and support with a focus on responses from PLWHAs, villages and religious organisations from China, Malaysia, Cambodia, Vietnam, Korea and Thailand.

**Information about the publication may be found at:**

http://www.unescap-healthdev.org/resources/formpub.htm

They also have examples of good practice in these areas at:

http://www.unescap-healthdev.org/practices/hiv/hiv.htm

**The Asian Development Bank (ADB)**

ADB is a multilateral development finance institution dedicated to reducing poverty in Asia and the Pacific. Established in 1966, the bank is owned by 61 member countries, mostly from the region. The bank has its headquarters in Manila with 24 other offices around the world. The ADB aims to help improve the quality of people’s lives by providing loans and technical assistance for a broad range of development activities. The ADB supports actions to prevent and control AIDS at regional and country levels guided by their Long-Term Strategic Framework (LTSF) and poverty reduction strategy.

Examples of their HIV/AIDS projects and support include:

- **Regional investment programs** such as “Community Action for Preventing HIV/AIDS” which focuses on HIV/AIDS prevention activities in source and destination areas of mobile populations in Cambodia, Lao PDR, and Viet Nam.
- **Working in collaboration with several UN agencies and AusAID** to support international and regional conferences, study tours and other information sharing activities including HIV/AIDS related web-sites. The ADB was a contributor to the 6th ICAAP.
- **The regional project Community Action for Preventing HIV/AIDS**, which is developing community based models for AIDS care in Cambodia, which could later be replicated in Viet Nam and Lao PDR.
- **A Rural Health Project in Viet Nam** which seeks to strengthen communication activities to help people change their behaviour and community organisations aimed at helping the prevention of HIV/AIDS.

The ADB has made a clear commitment to responding to HIV/AIDS (see their website at www.adb.org/AIDS) and a number of their projects, as seen above, focus on community organisations and vulnerable populations.
Association of Southeast Asian Nations (ASEAN)

The ten-country Association of Southeast Asian Nations (ASEAN) was established on 8 August 1967 in Bangkok by the five original Member Countries: Indonesia, Malaysia, Philippines, Singapore, and Thailand. They have since been joined by Brunei Darussalam, Vietnam, Laos, Myanmar, and Cambodia.

The highest decision-making organ of ASEAN is the Meeting of the ASEAN Heads of State and Government. The ASEAN Summit is convened every year. The ASEAN Ministerial Meeting (Foreign Ministers) is held on an annual basis. Ministerial meetings on several other sectors are also held.

The ASEAN Task Force on AIDS (ATFOA) was established 1993, in response to the call of the 4th ASEAN Summit held in 1992, to strengthen regional coordination, build regional capacity and address cross border issues. It has met almost every year since.

The First ASEAN Work Programme on HIV/AIDS Prevention and Control was implemented from 1995 to 2000. The ASEAN Cooperation Forum on HIV/AIDS was held in Bangkok in February 2003. ASEAN regularly sponsors workshops on HIV/AIDS. Two HIV/AIDS-ASEAN Regional Workshops of Islamic Religious Leaders have been held, one in 1998, and one in 2000. One on Population Movement and HIV/AIDS was held in 1999.

All of the above mechanisms to a greater and a lesser extent are opportunities for policymaking and the inclusion of affected communities. Higher level meetings may be more difficult to take part in, but NGOs and CBOs should lobby to ensure that any declarations resulting from these reflect an understanding of the need to involve affected communities in responding to AIDS. Workshops and forums will likely be more easy to participate in, and can be opportunities for policy-making at the events themselves as well as opportunities for planning and discussing how ASEAN can best implement strategies on involving communities.

Case-Study: The ASEAN Regional Workshop on HIV/AIDS: Addressing Stigma and Discrimination was scheduled to take place in Melaka, Malaysia, 25-27 April 2003. The World Youth Foundation (WYF) coordinated youth participation in the forum with the aim to raise issues about youth and AIDS, resulting in a number of concrete outputs including an ASEAN Youth Forum Declaration, an ASEAN Regional Youth Network on HIV, and preparing young people to participate in the 2nd International Youth Conference on HIV/AIDS scheduled for June 2003.

The Commonwealth of Nations

The Commonwealth is a unique family of 54 developed and developing nations around the world. It represents one third of the population of the world and just under 2 billion people. In the Asia and Pacific region, members include Malaysia, Singapore, Bangladesh, India, Pakistan, Australian, New Zealand and much of the Pacific Islands. Every two years, the Commonwealth Heads of Government meet. In December 2003, they are scheduled to meet in Abuja, Nigeria. A Civil Society Meeting often takes place at the same time as CHOGM, and there are a variety of meetings and events to promote civil society organisations. Commonwealth Ministerial meetings also take place regularly - and the Commonwealth Health Ministers Meeting and Commonwealth Finance Ministers
Meeting could be important places to lobby for attention to AIDS issues. The Commonwealth, through CHOGM, has made statements about HIV/AIDS and their small secretariat in London has sponsored included HIV/AIDS in its activities on a small scale.

Case-study - The Para 55 group (www.para55.org): Para55.org is a working group mainly comprised of Commonwealth Health Professional Associations and was formed following the meeting of Commonwealth Heads of Government held in Durban, South Africa in November. Noting the paragraph on HIV/AIDS, para 55, in the Communiqué issued 1999, they saw an important opportunity to lobby the Commonwealth to make good their commitment. Their main focus is on influencing Commonwealth meetings but they have also made presentations, organised seminars, and produced publications.

International Treatment Advocacy Coalition (ITAC)

The International Treatment Advocacy Coalition (ITAC) is a coalition of partner organisations including people living with HIV/AIDS and their advocates, NGOs, governments, foundations, the private sector, academic and research institutions and international organisations. It was established in 2002 with a shared goal to expand access to HIV treatment for all people living with HIV/AIDS who need it, in line with the goals of the Declaration of Commitment of the United Nations General Assembly Special Session on HIV/AIDS. They invite partnership with anyone involved in the scaling up of treatment access. While relatively new, the coalition could be an important force in treatment access, a movement that has been driven and will need to continue to be lead by the needs of PLWHAs and affected communities. More information On ITAC can be found at http://www.itaccoalition.org

Conferences

International AIDS Conferences (IAC)

International AIDS Conferences began with Atlanta (USA) hosting the IAC in 1985. Conferences were held annually until 1994 when they became biannual. The conferences are important opportunities to discuss the progress of the global response to AIDS, for participants to learn from each other, and for the development of collaboration between scientists and community. The Community Forum which precedes the official program of the IAC is an opportunity for community activists to meet with each other before the conference starts.

IACs offer many important opportunities, including the opportunity for:

- Civil society representatives to meet with other sectors: government, science, business
- Civil society representatives to make presentations on why affected communities must be involved in the response to AIDS
- CBOS and NGOs to meet, plan, and organise to increase our representation in policy-making.
- Activists to attend skills-building workshops which increase our capacity to be involved in policy-making and to advocate for our inclusion in policy-making
- International and regional networks to meet and strategize
Today, IACs include among their co-sponsors and co-organisers, the International Council of AIDS Service Organisations (ICASO) since 1993; the Global Network of People Living with HIV/AIDS (GNP+) since 1996 and the International Community of Women Living with HIV and AIDS (ICW) since 1998.

**Case-Study** - Montreal: The Montreal (Canada) conference in 1989 marked a watershed event in the history of IACs and the epidemic. Until then, IACs were primarily the province of scientists. During the Montreal conference, approximately two hundred or so HIV/AIDS activists stormed the stage and took their place at the heart of the conference. A person living with HIV “officially” opened the conference “on behalf of people with AIDS from Canada and around the world”. The difficult dialogue between science and community had begun. The activist agenda was broader than conference-related policy though and called for concrete action from the outset. During the 1989 IAC, the US-based AIDS activist group, Act-Up, released its first Treatment and Data Report, calling for a parallel (clinical trials) track to speed up access to drugs for the treatment for AIDS-related conditions. Talks began with government and industry in the USA to make expanded drug access a reality. 

**Case-Study** - San Francisco: In San Francisco (USA) in 1990, scientists joined activists in protesting the restrictive US policies on immigration and travel restrictions applied to people living with HIV. These policies are still in place. Activists/community representatives now found themselves sitting on session panels with scientists. San Francisco was a milestone in political mobilization. It marked the conferences as a political event for arguably the first time.

**Case-Study** - Sex Worker Mobilization: In order for affected groups to become involved in policy-making, they must first have some level of mobilization. Priscilla Alexander from the North American Task Force on Prostitution commented recently: “The conferences have had an impact. They have certainly facilitated international communication between sex workers’ rights organisations, out of which have grown sex workers’ rights groups in countries far from the Europe/North America/Australasia of the birth of the movement.”

**International Congress on AIDS in Asia and the Pacific (ICAAP)**

The first meeting of what was to become known as the International Congress on AIDS in the Asia Pacific was convened in Canberra, Australia in 1990. Meetings have generally taken place bi-annually following this meeting and have taken place in Delhi, Chiang Mai, Manila, Kuala Lumpur and Melbourne with the next one scheduled for Kobe. ICAAPs are smaller versions of the IAC, and the opportunities for policy-making and advocacy are the same as what was described in the section above. However, because the conference is much smaller, only a few thousand people rather than the thousands that attend the IACs, ICAAPs can be a more manageable atmosphere in which to achieve these aims.

Case-Study - the Seven Sisters: At the 6th ICAAP in Melbourne, the seven organisations that make up the Seven Sisters co-ordinated the Community Forum for the first time. By doing this, the Coalition aimed to assist new-conference goers to better utilize the conference, to provide the space and opportunity for community activists to meet before the conference, and to identify issues of importance to discuss and advocate for during the ICAAP, in particular, the concerns of the network around the inclusion of affected communities in responses to HIV and AIDS.

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5 From: “A brief history of the IAC - selected highlights (1)” HDN Moderation Team on the INT-AIDS listserv
6 ibid 5
7 Comment from “IACs: What are they for? (3)” INT-AIDS listserv, 5 May 2003
Meetings

Asia-Pacific Leadership Forum on HIV/AIDS and Development

Funded by AusAID and a number of other donors, the Forum will involve a number of training workshops starting in 2003 for senior government officials in the region. Workshops will address a wide range of topics and are aimed at increasing leadership, commitment and skills for responding to HIV/AIDS. There also may be a parallel set of workshops for community leaders.

Meetings on Treatment Access

International Roundtable in Canberra

In September 2002, an international roundtable entitled "Increasing Access to HIV Treatment in Resource Poor Settings" took place over five intense days of case studies and discussions. Nearly one hundred key individuals working in the field of HIV/AIDS, primarily from the developing world took part. They included PLWHAs, community representatives and activists, NGOs, academics, government officials and both researched-based and generic AIDS drug manufacturers. A particular strength of the meeting was in bringing participants together across sectors. It is hoped that the lessons learned and inspiration gained from the gathering will contribute to increasing access to treatment in the Asia-Pacific region.

International Treatment Preparedness Summit in Cape Town

In March 2003, nearly 125 participants from 67 countries attended the International Treatment Preparedness Summit, an event "organised by an ad-hoc coalition of treatment activists from around the globe" and sponsored by over a dozen donor organisations. They were joined by representatives from these donor organisations as well as by volunteers and local organisers with the main aim of establishing organisations and movements for increasing treatment access where none exist, and strengthening those that already exist. This meeting was organised by and focused on activists. While it is unlikely that a similar international meeting will take place, regional summits are expected to take place in the near future and lessons learned from the summit are hoped to be carried into local and national work.
Chapter Conclusions

Advocacy towards becoming involved in policymaking at any of these forums is usually two-fold. Firstly, it aims to support the general principle of ensuring that the voices of community are involved in the response to AIDS at all occasions and on an on-going and continuous basis. So, the advocacy is to ensure good process and principles. Secondly, it aims to support the needs and demands of those communities - to work towards various outcomes. These would vary depending on the event and circumstance. One of the examples given is of a youth NGO working towards the establishment of a youth task force on AIDS. Other demands might relate specifically to general projects involving capacity-building, treatment access or care initiatives. Or they may ask for specific items such as legislative change to support an enabling environment.

The opportunities listed here are not meant to be comprehensive but to include the most important of them as well as examples of other types of key events. AIDS is changing the world, and the world of AIDS changes very quickly. Institutions and meetings may continue to operate or meet regularly, or they may be replaced by other similar or different fora. However, the examples in this chapter should be seen like the case studies in Chapter Three of Part I of All of Us Count: each one is different and offers different lessons, opportunities and obstacles.

It is important to remember that all of these forums offer opportunities to build relationships and do further policy-making and advocacy, and if your efforts are not successful at first, they may sow the seeds for success in the future.

*Please carry on with your good work, and we hope this publication is of use to you.*