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 1

building capacity and building community

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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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 1:

- Explains why the involvement of affected communities is important
- Describes a human rights approach which provides the basis for the empowerment of affected communities to be involved in the HIV/AIDS response
- Highlights examples of the successful involvement of affected communities, as well as how this has increased the effectiveness of the organisations involved. Some examples of capacity-building in Community Based Organisations (CBOs) and Non Government Organisations (NGOs) are also given.

Chapter 1 of Part 1 describes the reasons for this publication, 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 (PLWHAs). Frameworks such as Gender, the Prevention-Care Continuum and Access to Treatment are presented. The chapter uses the example of PLWHAs 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 this publication, that of a human rights approach to HIV/AIDS. After defining the concepts of human rights in relation to HIV/AIDS, the question is explored of what constitutes an effective response to HIV/AIDS. The chapter looks at human rights issues pertaining to AIDS and to affected communities such as 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 this publication. Examples of how organisations involve affected communities are given in ten case studies which include 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.
Part 2 of the publication which is published as a separate document:

- 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 CBOs and 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 of Part 2 introduces the Seven Sisters network and each of its members.

Chapter 3 of Part 2 provides a listing of regional and international opportunities for advocacy including institutions and conferences.
Chapter 1  The Involvement of Affected Communities in Responding to HIV and AIDS

Why this publication?

Because we assume that most readers of this publication work in the field of AIDS, it is possibly unnecessary to note the following: The latest UNAIDS estimates from 2003 report that 40 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 this publication 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 the 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. This publication aims to address these two important issues.

Before doing any of this, it is important to “set the scene”, in other words, to describe how we will explore the issues, from what perspective, and what we intend to achieve by doing so. It is also necessary to describe how particular concepts or ideas will be used to ensure a clear understanding of the key messages in this publication.
Intended Audience

This publication is a project of the Coalition of Asia Pacific Regional Networks on HIV/AIDS (the Seven Sisters) which is made up of NGOs and networks which are linked to community-based organisations (CBOs), non-government organisations (NGOs) and individual activists.

Therefore, the intended audience for this publication is members of these networks: organisations or individuals who are working, or have some experience, in the field of HIV/AIDS. It is hoped that this publication will be useful as a resource for the themes it deals with.

This publication is also intended for use as an advocacy tool with decision-makers, whether associated with local or national governments, or regional and international institutions. But we also hope it will reach these individuals directly so they will read our message of involving affected communities in a response to HIV and AIDS.

Because the Seven Sisters is located in the Asia-Pacific region, the focus of this publication is regional and uses regional case-studies. However, because the region is so diverse - including countries as different from each other as Mongolia, Australia and Kiribati - we hope that this publication can also be read and understood by community organisations and activists, and decision-makers from all regions of the world.

Style and Language

This publication is meant to be widely accessible so we have attempted to use easy-to-understand language and to avoid using slang, jargon or colloquial phrases’ - or to at least explain them when they appear!

We also use the more personal first and second person narrative (you, we) rather than the objective third person narrative form. We use the phrase “you” because we intend this publication to be read by an audience, and hope that it is “you” who will be using it to improve local, regional and global responses to AIDS. We do not pretend objectivity because we are not objective - the global response to AIDS needs to be improved and we hope that this publication will contribute to that."

1 Often, publications on HIV/AIDS use slang or colloquial language which may not be understood in different countries or cultures, or use ‘jargon’ - specific language that may not be understood by those unfamiliar with HIV/AIDS work.

2 In many English-speaking countries, students are taught to write in the third-person and to avoid the use of first and second person: I, we, you. This is so that writing appears “objective”, so that it takes the writer out of the writing, and presents information which is supposed to be neutral and free of values and judgement. However, academic theorists working in the schools of “critical theory” and “post-modernism” point out that a so-called objective viewpoint can obscure other viewpoints. While there are many viewpoints of historical events, if only one version is recorded, that one may be seen as the “truth”. Writers may attempt to be “objective,” meaning that they are free of political and moral viewpoints, but it is impossible to be truly objective. We think, live and write from our own experiences, which will be shaped by factors including society, culture, history and economy.
Why involve affected communities?

This publication proposes that all responses to HIV/AIDS should involve affected communities. This means that the experiences of people who are living with HIV/AIDS and people who are more likely to be infected by HIV/AIDS should be used to shape prevention, care, treatment and support initiatives, as well as strategies, policy and advocacy on HIV/AIDS.

Why should this be done? The reasons for the involvement of affected communities comes under two main categories: ethical and practical. Ethics can be defined as “Standards of conduct that guide decisions and actions, based on duties derived from core values.” Core values that community representatives advocate include the involvement of people in decisions that affect them, and working towards positive partnerships between people working on an issue.

By involving affected communities in the response to HIV/AIDS, it is made clear that AIDS is a shared responsibility between governments and communities for finding sustainable, appropriate and responsible responses. Community involvement is also important for building relationships with and among participants to develop a partnership approach.

These ethical reasons for involving community also have practical implications. While a sense of shared responsibility for AIDS between governments and communities is a good thing in itself, it also assists in the response to AIDS by increasing the commitment of communities, and not only governments, to find solutions.

It also ensures that solutions will be workable. Affected communities will have local knowledge and solutions which should guide decision-making processes. The involvement of community ensures that actions will be as acceptable and appropriate to the local community as possible, and can be effectively implemented. This can be contrasted to a situation where an international NGO tries to implement an AIDS project that they have developed in isolation from the community where the project is to be implemented in. Will community members accept the NGO? Will the project components be applicable to the local situation? Is it ensured that the project relates to the needs of the communities concerned?

Community education will also be developed by involving affected communities. Communities will be informed about programs and projects that are to be carried out. This can ensure that they are accepted, but it can also lead to a process where the concerns of the community are incorporated into the programs and projects to make them more effective.

AIDS responses involve people and communities. Theories or plans should not be developed in isolation from the communities where they are to be carried out, whether that is in a government office, or a foreign country. For projects to be successfully carried out at the community level, the involvement of affected communities must be assured.

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3 The HIV and Development section of the United Nations Development Programme (UNDP) recommends the following about HIV-related language: “It is better if the vocabulary used is drawn from the vocabulary of peace and human development rather than from the vocabulary of war. For example, synonyms could be found for words like “campaign”, “control”, “surveillance”, “fight”, “battle” etc. See more info at: http://www.undp.org/hiv/policies/langpole.htm

4 The Ethics Resource Centre at www.ethics.org
This is no easy proposition though, and in order to make it a reality, cooperation will be needed between everyone involved. Decision-makers will need to be open to the involvement of affected communities. Affected communities and the CBOs and NGOs that work with them will need to engage in a continuous process of reflection to ask questions such as:

- How are our interests best represented?
- What form of involvement do we need to advocate for?
- Who can best represent our interests?
- Do we have the resources to support this process?
- Is the involvement “authentic?”

Strong statements about community involvement have been made in relation to research and clinical trials. For example, in the UNAIDS document, *Ethical consideration in HIV preventative vaccine research*, Guidance Point 5 on community participation states:

To ensure the ethical and scientific quality of proposed research, its relevance to the affected community, and its acceptance by the affected community, community representatives should be involved in an early and sustained manner in the design, development, implementation, and distribution of results of HIV vaccine research.

If we are to apply this recommendation to a broader response to HIV/AIDS and not just to research and trials, involvement of affected communities is recommended at all levels of a process (design, development, implementation and distribution) and this involvement is recommended to be early and sustained.

**What is Involvement?**

Now that we’ve argued that “involvement” is important, an exploration of what is involvement is necessary. In this publication, “involvement” describes an interaction between at least two parties. Many CBOs and NGOs have become involved in HIV/AIDS issues, or were formed in response to the HIV/AIDS epidemic. However, the mere existence of these organisations, or examples of their activities, is not enough to constitute involvement.

Involvement refers to a broad HIV response, usually lead and controlled by national governments and influenced by regional and international bodies, and a space within this response where affected communities, or the CBOs and NGOs that represent them, take part in a positive relationship with other stakeholders such as government, industry, scientific or economic institutions.

Involvement ranges both in level and length of time. Involvement may involve an extensive partnership between two parties, for example, an in-depth collaboration between a government and a community group where a strategic document is developed by both parties. Or involvement may mean more simple interactions, such as the representation of a community organisation on government committee, or a consultation on a particular issue between industry and civil society. Involvement may take place in a sustained manner over a long period of time, or it may be a one-off occurrence.
While we would generally argue that involvement should be both extensive and sustained, this may not always be possible or appropriate. What we would always argue for though is that the “involvement” of affected communities is meaningful, meaning that communities have an authentic voice to speak with, and that the interaction has a level of equality and respect in negotiations and agreements. It involves processes that are open, responsive and effective for incorporating the opinions and lived experiences of community members.

**A bad kind of involvement:**

- When governments or projects go through a process of consultation with community members where the opinions of community members cannot or will not be incorporated into decision-making.
- Token representation where one individual or organisation will be put on a committee, but will not have power to negotiate or speak. This may be because they are the sole community representative and will find it difficult to present views which differ from the majority. Or it could involve being pressured by the people who run the committee to vote or speak in a certain way.
- Where there are problems in terms of resources. While a government may offer a position on an advisory board to a community organisation, there is no guarantee that the government will offer assistance to cover costs associated with that position and that the organisation itself can afford them.

It is also important to press for involvement in governing boards. Global, national and local organisations that work with HIV/AIDS sometimes reserve seats on governing bodies for representatives from affected communities. This level of involvement can be particularly valuable for incorporating the views of affected communities into decision-making processes, although it may be difficult in terms of time or expertise for the individual involved. The Global Fund has seats on its board for NGO and CBO representatives from both the developed and developing world, as far as a designated seat for affected communities.

Another point of advocacy is to ensure that involvement is not limited to one area of the response. In the Asia-Pacific region, there are a number of day-care centres where PLWHAs have access to medical services and information, and some of these are run and managed to PLWHAs. This is one kind of involvement - involvement in the national care and treatment components of an overall response to HIV/AIDS - and it is positive. However, some governments feel that this is a sufficient example of PLWHAs involvement in a response to HIV/AIDS and do not involve PLWHAs in higher level decision-making processes.

The involvement of affected communities may require the mobilization of these communities. This basically means different ways for individuals to come together in support of a cause or interest, and may involve informal or formal meetings, training and skills-building sessions, and networking. The two concepts are not the same but are related. Community mobilization may be necessary in order for involvement to occur, so that individuals, groups or organisations representing affected communities have some level of skills, power, cohesion and voice to feed into their advocacy efforts.
There is no fixed definition of involvement, and the level of involvement that will be desirable will vary according to the situation. However, if we are to advocate for the involvement of affected communities in responses to HIV and AIDS, we will need to define for ourselves, in each situation, the level of involvement that we want, and figure out how to make it as meaningful as possible.

**Why Involve Affected Communities?**

- To develop shared responsibility
- To develop partnerships for finding solutions
- To develop community education
- To use local knowledge and expertise
- To ensure that projects and programs:
  - are accepted by the communities
  - are appropriate to the communities
  - will be effectively implemented

**Terminology**

This publication will often use the terms found below and it is therefore necessary to develop a shared understanding between writers and readers of how the terms will be used.

**Community**

“Community” itself can be a difficult word to define, and is used in many different ways. Dennis Altman notes that it is “one of the most complex and imprecise in the vocabulary of social science.” In much current work on HIV/AIDS today, community is loosely defined as a group of people who share a common characteristic. This can be a narrowly-defined community, for example, female sex workers who inject drugs, or it could encompass a much broader constituency, for example, the organisation, the International Community of Positive Women (ICW+), would count all HIV positive women as being part of the community that they serve. Sometimes, the categorization of “community” brings together people who may not have much in common. For example, a gay man in Australia and a married bisexual man in Sri Lanka may both be considered Men who have Sex with Men (MSM) but share little in other ways. However, the concept of community, however unclear it may be at times, serves a purpose. It can be used to mobilize people for a cause by bringing them together and working towards common aims. It can be used to call attention to a particular social issue such as AIDS that affects certain groups of people more severely because of characteristics such as race, ethnicity, sexuality, or profession.
In most countries in the world, HIV infections first occurred in particular populations: in many Western countries, haemophiliacs and gay men; in other countries, sex workers and their clients, drug users who share needles, or people working in particular professions such as mining or transportation. Migrants, refugees and ethnic minorities may have higher rates of infections. The indigenous population in Australia has a higher infection rate than the general population. In defining these groups as affected communities, it is important to examine the particular factors of why they were infected and to develop strategies for prevention, care, treatment and support. It should also be noted that individuals can belong to several communities at once, and that communities are not exclusive (i.e. a transsexual female sex worker who injects drugs).

**Affected communities**

Affected communities has several meanings. It refers to communities of people who are at greater risk of HIV infection. However, it also refers to communities where members have already been infected. Because people living with HIV/AIDS live in society, and therefore are connected to spouses, family, co-workers, and friends, these communities are affected by HIV and AIDS. Finally, people who have been infected by HIV have come to constitute another affected community, that of people living with HIV/AIDS. Debate takes place occasionally about whether to involve only infected individuals (PLWHAs) or whether to also include affected individuals, which could include uninfected family members or friends, in particular situations.

**Vulnerability**

The phrase affected communities is also sometimes linked with the concepts of vulnerability. Individuals or communities are said to be “vulnerable” to HIV infection when their social circumstance makes them more likely to be infected than others. For example, women are often said to be vulnerable because they lack the power to say no to unwanted sex with their husbands. An injecting drug user would be more vulnerable to HIV infection in most societies because the illegal nature of their activities means they are less likely to have either the information or clean needles with which to protect themselves. There are variations in the nature and extent of vulnerability.

**Marginalisation**

Most communities vulnerable to HIV infection are marginalised in some way. This means that they are made marginal, or smaller, in terms of their social power because of a particular social factor. Sex workers are marginalised by a society that does not want to recognise their work as a legitimate occupation. This makes it more difficult for them to work in safe situations. Men who have sex with men are marginalised because most societies do not approve of sex between two people of the same gender. The form of their marginalisation may be a lack of equal rights and recognition, or may take an active form of hostility such as police harassment or public violence.
When individuals are infected, regardless of what community they may be associated with, they are subject to further marginalisation. People living with HIV/AIDS face discrimination, prejudice, hostility and ignorance because of their status, and the resulting marginalisation ranges from the personal, such as a loss of self-esteem, to legal issues such as losing the right to marry (as was proposed in India) or the right of employment (where anti-discrimination legislation is not in place).

**Empowerment**

An opposite word to marginalisation is “empowerment.” Rather than taking power away from individuals, empowerment seeks to give it. It can be defined as a process which increases the capacity of individuals or groups to make effective choices and to transform those choices into desired actions and outcomes. This can involve building resources and financial capital, but can also mean an improvement of skills and knowledge. Empowered people have freedom of choice and action. This in turn enables them to better influence the course of their lives and the decisions which affect them.

Perceptions of being empowered vary across time, culture and aspects of a person’s life. However, empowerment will often include common elements such as access to information, inclusion and participation, the accountability of those who have power, and the improvement of the capacity of local organisations.

Unless individuals and organisations have a basic level of empowerment, it will be difficult for them to be involved in responses to HIV/AIDS, and impossible to take part in higher level advocacy and policy-making.

**CBOs/NGOs**

The way that affected communities will be involved in a response to HIV/AIDS will often be through organisations made up of people from affected communities, or organisations that represent them. Many terms are used to describe these bodies, all with slightly different connotations. We prefer to use the term Community-Based Organisation (CBO) which refers to groups which “represent the views of and act on behalf of their own members.” The term Non-Governmental Organisation (NGO) will also be used to refer to an organisation that works outside of government structures. NGOs are sometimes CBOs if they work directly in communities with their input and involvement, but NGOs, especially international NGOs, may play a role as facilitating projects and processes rather than doing work that comes directly from communities.

The most frequently used term in this publication to describe an organisation that represents affected communities is CBO. However, other phrases are used to describe community-based organisations that work in AIDS. The term AIDS Service Organisation (ASO) refers to all organisations other than government that work on AIDS. Others propose the term “self-help” group or organisation. At times, you may hear the phrase “civil society”, coined by the Italian scholar Antonio Gramsci, to describe a set of institutions through which society organises and represents itself autonomously from the state. By this definition, civil society includes CBOs, NGOs, church or faith-based organisations, and even business.

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6 Broadhead and O’Malley as quoted in Altman, Dennis (1994)
7 See Altman, Dennis (1994) p. 27-28
8 Altman, Dennis (2001) p. 74
Which Affected Communities?

PLWHAS and GIPA

The phrase “Person Living with HIV/AIDS” (PLWHAs) is found in altered forms around the world: Person With AIDS (PWA), Person Living with HIV/AIDS (PLHA). Some publications prefer to use the phrase “HIV Positive Person” or use the abbreviation in small-case (PLWHAs). Indigenous abbreviations such as the Indonesian ODHA are also in use.

Dennis Altman describes the growth of the concept of PLWHAs in Global Sex as a “significant factor in breaking down the medical dominance of the epidemic.” Building on earlier models of gay “coming out”, PLWHAs in western countries asserted a space in which they spoke of their own experiences and shared their own expertise - which in some instances was equal to or better than found in medical establishments. They demanded partnerships. They demanded access to treatments.

This concept has now been adopted and adapted internationally. However, it is not a simple task, nor a straightforward concept. Peter Canavan, then president of Australia’s National PLWHAs organisation, NAPWA, said at the opening plenary of their 8th national Conference, “The Australian HIV community-based experience has been able to be effective because the community constructs were in place before the disease appeared.” In other words, the strength and success of PLWHAs organizing was based upon a well-established and organised gay movement.

Can strong mobilization of PLWHAs take place in other locations and social contexts? In a number of African countries, the sheer number of PLWHAs and their struggle for their lives has created powerful organisations such as the Treatment Action Campaign of South Africa. However, in the Asia-Pacific region, most PLWHAs organisations, if they exist at all, are fragile and are made up of a small number of dedicated and brave individuals. So, a crucial question is how to sustain these organisations so that they will be able to advocate for their involvement in responding to HIV/AIDS.

The concept of Greater Involvement of People living with HIV/AIDS (GIPA) is one of the inspirations for and starting points of this publication. At the 1994 Paris Summit, 42 governments signed the declaration. This concept of involving affected communities has been adopted and used by other affected communities, such as we are doing in this publication.

However, a question that deserves further exploration is how well the concept of GIPA is working. GIPA hopes to provide PLWHAs with the skills able to participate in policy and decision-making. However, consultants Bill O’Loughlin and Timothy Mackay comment that:

"It has not proved sufficient to rely upon PLWHAs having the skill and capacity to take exclusive responsibility for implementing GIPA. Instead, it is necessary to get all the other actors in the epidemic to understand the value of GIPA and the role and responsibility that they can take in supporting it."
This also means that where PLWHAs are unable to represent themselves (due to lack of resources or skills, or difficulties faced from being marginalized and stigmatised), their views and opinions still need to be incorporated. Decision-makers need to find processes that facilitate this. The same could be said about situations involving others from affected communities - if representation is not possible, how can we still ensure involvement?

**Sex Workers**

The first organisations for sex workers started in the early 1970s in the USA and Europe. Coining the phrase themselves, “sex workers” argued that adults should have the right to use their bodies to make money, and should be protected from exploitation and danger in making use of that right. Dennis Altman, in Global Sex, reports of sex worker groups in forty countries including strong groups in India and Thailand, as well as other groups in Ghana and Papua New Guinea which may include sex workers without making this the defining feature of the organisation.

Altman points out that “most people who engage in sex for money have no sense of this comprising their central identity, and they may well be repelled by attempts to organise around an identity they would strongly reject.”

However, sex work is incredibly stigmatised. They are attacked from religious and conservative groups as a danger to health, morality and social order, and attacked by some feminist groups as being exploited victims of poverty, patriarchy and their gender. Donna Hughes in the National Review attacks sex work organisations active in HIV/AIDS work: “Groups...abandon whatever moral sense they have, in order to ... give them condoms and medical services.” Sex workers are “victims entrapped in sexual slavery.”

In various parts of Asia, sex workers have been found to be particularly vulnerable to HIV infection (Cambodia, Thailand, India). So, this publication argues that any response to HIV/AIDS in the region should include involvement of sex workers and their organisations. However, as with drug use (see below), sex work is so “heavily stigmatised and criminalized it may indeed be impossible to develop communal organisations; the best one can do it to develop advocacy organisations which will seek to represent them.”

**Men who have Sex with Men (MSM)**

In the Western world, it has been gay communities that have been hit hardest by HIV and AIDS. The term “Men who have Sex with Men” (MSM) was coined as a way to describe men who have sex with men but who rejected or did not ascribe to an identity based on sexual practise such as “gay” or “bisexual”. Altman points out that “Ironically the term . . . fairly quickly became used in ways which just repeated the old confusions between behaviour and identity.” The term is also used by men or groups who reject “western sexualities” while they seek to find their own names and identities, for example, the Tongzi movement in the Chinese-speaking world, and the use by the Naz Foundation of the term MSM to describe Indian identities such as kathi.
However, there is an imprecision in the way that these terms are used in HIV/AIDS work. Whether located in a western or non-western country, men may choose to describe themselves as gay, bisexual, or even the term queer, while other men will either not categorize themselves or refuse to do so. People working in HIV/AIDS may alternate between speaking of “gay communities” and “MSM communities”.

What is important to note is that men who have sex with men have been found to be at risk in many countries around the world, not just Western ones. Many governments often deny that sex occurs between men in their countries and propose that it is a Western concept, when no research or surveillance has been done to assess how much is happening, where it happens and what kinds of sexual identities are being adopted. Discrimination and marginalisation of same-sex behaviour causes men to be wary of identifying themselves in such ways. 17

**Injecting Drug Users (IDU)**

In several countries in Asia, injecting drug users (IDUs) represent the largest group of those who are HIV-positive. While drugs are ingested in many ways, including by smoking and by taking pills, it is injecting drug use (that involves the sharing of unclean needle) which is a particularly efficient and rapid way for HIV infection to spread. In many countries, a high percentage of IDUs are infected.

In this publication, we will most often refer to IDUs in relation to HIV and AIDS because of the role that injecting drugs has in transmission. However, drug use can also affect a person’s abilities in a situation to protect themselves from infection - i.e. their mental state will be affected and they may not use condoms and lubricant while having sex, or use clean needles when injecting.

In talking about discrimination and human rights issues for drug users, it is more useful to refer to the general category of drug users without distinguishing between those who inject and those who don’t. Drugs users around the world, and in the Asia-Pacific region face extreme stigmatisation and marginalisation on many levels: legal, political, and social.

For example, Thailand’s “War on Drugs”, a 3 month campaign launched on 1 February 2003 has been criticized by human rights bodies for extra-judicial killings, “blacklists” of suspected drug users or dealers, rehabilitation programs, and imprisonments. The numbers of people involved include possibly over 2,000 killed, over 15,000 imprisoned or sentenced, and over 280,000 people sent for “rehabilitation.” 18 We believe that HIV infection is best controlled in drug user populations by initiatives that reduce harm associated with drug use, rather than by criminalizing drug use and attacking drug users.

It should be noted that, as in the cases of sex workers and MSM, while we define these communities to specifically address the issues relating to them and AIDS, drug use is only part of a drug user’s life. They are members of families. They probably have an occupation. It is unlikely to bring benefit to themselves to associate with an identity called “drug user.”

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17 Altman’s chapter in Global Sex “The Globalization of Sexual Identities” (2001) is a useful starting point for further reading and includes extensive footnotes to other references.

Migrants and Mobile Populations

There is an increased volume of mobility in the Asian region including Filipino domestic workers, sex workers working in the border areas of the Mekong Region, and more. Match this with the rapid spread of HIV throughout the region and there is concern about the increased vulnerability of migrants in terms of health in general and STD/HIV/AIDS infection especially.

Migrants are vulnerable to HIV infection for a number of reasons. National governments of migrants-sending countries are not able to protect their leaving migrants from the increased vulnerability that is the consequence of migration. But governments of migrants-receiving countries are often not interested in assisting foreigners. Furthermore, AIDS education messages are not in the languages of migrant workers and health services are much harder to find and to approach for migrants. Meanwhile, the HIV pandemic has special consequences for the human rights of migrants that have to be addressed.

While migrants are generally not in the position to be able to form advocacy organisations, CARAM-Asia, a member of the Seven Sisters, works specifically on the issue of migration, mobile populations and HIV/AIDS, and this publication seeks to ensure that this affected community is also given attention.

Indigenous Peoples and Ethnic Minorities

Populations of indigenous peoples and ethnic minorities have, in general, been little explored in relation to HIV/AIDS but may have particular relevance to the Asia and Pacific region. In Australia, the indigenous population has been shown to have a higher prevalence of HIV infection than the population as a whole. Consideration should be given to what aspects of this particular social and cultural group have increased their vulnerability to infection. Similarly, ethnic minorities in different countries may have particular factors which increase their vulnerability to infection, for example, a lack of information in their own language, patterns of employment, and discrimination and racism that affects their self-esteem or access to healthcare. However, the two terms, indigenous peoples and ethnic minorities are not the same and should not be used interchangeably. Neither should the groups be considered automatically more vulnerable to HIV/AIDS. For example, in Fiji, native Fijians are an ethnic minority but might consider themselves the indigenous people of their country, while the sizeable ethnic majority of Indian background has considerable social and economic power. So, the consideration of indigenous peoples and ethnic minorities should be a question: are these groups particularly vulnerable to HIV infection in a given country and if so, what factors need to be examined?

Others

Although this publication focuses on the affected communities that are described above, there are other affected communities. It has been seen in a number of countries that once HIV infection has hit particular communities such as MSM, drug users, or sex workers, that these populations act as a “bridge” to the general population. Men who have sex with men may also be married or have sex with women. Drug users have family and friends. The clients of sex workers may infect sex workers or be infected by sex workers and then infect their wives.

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19 Indigenous: peoples who originally came from the land (i.e. in Australia, the aborigines). In North America, indigenous people are sometimes referred to as “First Nations People.”
This idea of “bridging populations” is used to advocate for a concerted response to AIDS involving these affected communities. This is because it has been seen around the world that effective programs and projects that target high-risk groups can prevent HIV infections in the broader population.

However, this also points to the fact that when HIV is in the broader population that different groups or communities are also vulnerable. For example, in Thailand, it has been noted that many women with HIV/AIDS have been infected by their only male partner. Therefore, in Thailand, women constitute a vulnerable community. As a further example, while no specific organisation has formed to advocate for youth and HIV/AIDS in the region, it could be argued that young people make up a significant part of new infections, and are particularly vulnerable to HIV infection. The dynamics of HIV infection shift and change, and it possible that particular groups based on occupation, location, or other factors will also become affected communities. In all cases, this publication asserts that their involvement in a response to HIV/AIDS is crucial.

Other Frameworks and Concepts

This discussion takes place in the context of other frameworks and concepts such as:

The Prevention-Care Continuum

We refer in this publication to “effective prevention, treatment, care and support initiatives.” This is to recognize that an effective response to HIV will include a variety of elements which relate to each other. In the past, HIV prevention and HIV treatment and care were viewed as being separate from each other. This model imagined an uninfected population receiving HIV prevention messages while HIV positive people would be involved in HIV care and treatment programs. In recent years, however, this separation has been challenged and the connections between prevention, treatment and care are being recognised, for example:

- HIV infections (unless through medical procedures) require an HIV positive person to be present. Therefore, it makes sense to include PLWHAs in prevention campaigns so that HIV positive people also receive messages about preventing infections. Not only this, in order for PLWHAs to be healthy enough to be involved in a response to HIV/AIDS, they will need access to treatment, care and support initiatives.
- In recent discussions on access to HIV treatment for PLWHAs, it has been pointed out that access to treatment promotes HIV prevention. If people think there is life-saving medicine, they are more likely to be tested. Meanwhile, at voluntary testing and counselling clinics, uninfected people can receive information about protecting themselves from HIV while HIV positive people can receive counselling on how to protect their partners.
- Involving family and friends of PLWHAs in care and support programs can also be a way of involving them in HIV prevention campaigns.

20 Beyer, Chris (1998) War in the Blood: Sex, Politics and AIDS in Southeast Asia London: Zed Books. p.16 - 35. “There is mounting evidence to show that the great majority of Thai women with HIV have had one sex partner in their lives — their husband, and have only one risk for HIV— his behaviour, which they may or may not be able to influence.”
21 Notably at the Barcelona International AIDS Conference in 2002 where many speakers declared that treatment and prevention cannot be separated from each other.
HIV/AIDS and Gender

While this publication does not go into an in-depth analysis of how gender affects the involvement of affected communities in a response to HIV, it is an important consideration or “framework” which should be used for discussions on AIDS. Gender should be a factor when considering each of the affected communities described in this publication, as well as for considering women as a community that is both affected and vulnerable to HIV infection.

The term “gender” refers to differences in social roles and relations between men and women. Gender roles are learned through socialisation and vary widely within and between cultures. Gender roles are affected by age, class, race, ethnicity and religion, and by the geographical, economic and political environment. Each must be examined in their own specificity. For example, the expected gender role of a young man will differ from that of an older man.

Gender roles can have both a positive and negative influence on responses to HIV/AIDS. Examples of positive gender roles could include an attribute assigned to older men to protect and act responsibly towards their families or an attribute assigned to women to provide care for their families. However, gender roles can also be negative, for example, in societies that condom violence against women including rape. The roles and expectations of gender can hinder a positive response to HIV/AIDS at all levels of society: individual, family, community and country.

Women in developing countries tend to be vulnerable to HIV infection as a group through social, economic, and political forces. As mentioned before, in some Asian countries, the biggest risk factor for a woman to be infected is through being married. Gender inequalities and lack of power within sexual relationships can make it difficult, if not impossible, for them to negotiate the use of condoms with partners. Also, lack of economic power can lead to vulnerability as some women are forced to enter into sex work or to form temporary partnerships to barter sex for economic survival. Furthermore, because of women’s greater biological vulnerability to infection transmission, they face greater risk of infection. Finally, women with HIV face high levels of stigma and discrimination.

Particularly in the developed world, men who do not fit into accepted gender roles may be marginalised. The needs of men who are gay, transgendered or otherwise identified are often ignored in many parts of the Asia-Pacific region where AIDS programs are likely to be implemented - even though men who have sex with men have been identified at high-risk for HIV infection in many countries around the world.

Access to Treatment

There are many issues relevant to HIV and AIDS today but none has become more of a priority agenda item than increasing access to HIV treatment for those around the world who need it. The moral imperative is quite simple: we have life-saving medicines for AIDS; millions need them; only a few have access to them; what can we do to change this? Strong community activism around the issue has been found in the work of Thai HIV/AIDS NGOs,
South Africa’s Treatment Action Campaign and the organisation of an international summit for activists in Cape Town in March 2003. Leading NGOs on the issue include Médecins Sans Frontières and the Consumer Project on Technology. A few governments have shown extraordinary leadership: Brazil and Thailand in particular. The World Health Organisation has called for treatment for three million people by 2005.

This issue is highlighted here because of its overwhelming importance, and because we can apply the themes of this publication to it. Treatment access initiatives and meetings should include involvement by affected communities. For example, sex workers and drug users should ensure that discussions of treatment access include their constituencies as well.

Where treatment access is possible, it has proved to be a key motivating factor for PLWHAs to adopt the identity “PLWHAs” - in order to get life-saving treatment, a person has to identify themselves as being infected. This process of identifying as a member of an affected community is an important step towards advocating for their rights and their involvement in responses to AIDS.

Many organisations and individuals around the world are working on treatment access with shared understandings and goals. The results of this “movement” include strengthened PLWHAs activism and meetings from local to international levels. Affected communities and the NGOs and CBOs that represent them should maximize their involvement in advocacy and policy-making opportunities that are arising because of the treatment access movement. Also, being involved in aspects of treatment access campaigns can be a way for affected communities to build skills in advocacy and policy-making, the focus of part 2 of this publication.

**Political Spaces for Community Mobilization**

The political space for community organisations to develop, which includes those that represent affected communities, will depend on the amount of space for community mobilization. This is higher in countries with political systems that have traditions of grassroots and community work, which includes most Western countries as well as some countries in Asia and South America.

However, even in countries with limited political space for political and communal organizing of the western sort, there are opportunities for community mobilization and education through the institutions of the state or the dominant political party. Altman points to “mass organisations” in developing countries such as Vietnam, Burma and China that resemble CBOs and have in some cases been mobilized to run AIDS prevention campaigns.

Therefore, while we advocate for the inclusion of affected communities in responses to HIV and AIDS, we recognise that this may be limited in different countries by the hostility of governments towards the formation and operation of organisations that could represent these communities.

See Altman, Dennis (1994) p. 24-26
Challenges to Involvement

The involvement of affected communities will have benefits to the overall response to HIV/AIDS as discussed above. However, the drawbacks should also be acknowledged and it is useful to look at obstacles to involvement. Research by the International HIV/AIDS Alliance working with the Horizons Project examines the experiences of community-based organisations in different countries in involving PLWHAs in their organisations. The first section discusses both positive and negative effects of GIPA in relation to the delivery of programs. The second section allows us to consider obstacles to involvement of affected communities by using the example of PLWHAs involvement in HIV/AIDS CBOs in Burkina Faso.

Positive & Negative effects of GIPA in CBOs in Four Countries

Summary: The International HIV/AIDS Alliance working with the Horizons Project undertook an operations research project to look at the involvement of people living with HIV/AIDS (PLWHAs) in the delivery of community based prevention and care services. The project found out how involvement both helped and hindered capacity building of these organisations.24

How does involvement of affected communities make the delivery of programs more effective? While the principle of Greater Involvement of People with AIDS (GIPA) has received support in dozens of forums, little research has been done to examine how it affects organisations and individuals. The Alliance in partnership with Horizons did an important diagnostic study examining the effects of the involvement of PLWHAs in prevention and care programs in Burkina Faso, Ecuador, India and Zambia.

Data were collected through interviews and focus group discussions with about 800 respondents. The study identified four types of involvement: PLWHAs use the services of NGOs (access); they support the activities of the organisations; either as support staff or as occasional volunteers (inclusion); they formally provide HIV/AIDS services (participation); they directly design services and manage organisations (greater involvement).

It was found that organisations derive positive effects from the participation and greater involvement of PLWHAs through

- **Improving the understanding of HIV/AIDS issues by service providers and their attitudes towards PLWHAs**
- **Increasing the credibility of the organisation with service users (when, for example, awareness messages are delivered by PLWHAs) and with donors**
- **Catalysing the integration of advocacy for PLWHAs rights with services.**

The effects of access and inclusion are limited because PLWHAs play only a marginal role in services.

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24 The text of this section is drawn primarily from a poster presentation by Horizons and the Alliance. The web reference is found at the end of the case study. The poster uses the abbreviation PLHA. We have substituted this with PLWHAs which we prefer to use in this document.
It was found that organisations derive negative effects from the participation and greater involvement of PLWHAs in the following circumstances:

- **When PLWHAs are the main providers of services or program managers, frequent illness and premature death may cause a disruption of services.**
- **Costs may be higher because of payment of benefits to PLWHAs and the need to train more employees.**

The inclusion of occasional positive volunteers with little training may jeopardize quality of services.

The study also found positive and negative effects for individual PLWHAs

**Positive effects**

- Peer counselling and support groups end self-isolation
- Participation and Greater Involvement may mean a dramatic increase in access in access to information on HIV/AIDS, acceptance of HIV status, and enhanced self-esteem
- Employment brings material benefits for PLWHAs working for NGOs
- These elements lead to improved psychological health and contribute to better physical health

**Negative effects**

- All types of involvement may cause stigma and discrimination depending on the visibility of PLWHAs within and outside the organisation and on preparation for disclosure
- Lack of training can lead to depression for asymptomatic PLWHAs involved occasionally in care for PLWHAs who are ill
- PLWHAs are exposed to burn out

The gatherings of this study show that while there are benefits to the involvement of PLWHAs in community-based programs, there are also drawbacks. Advocates for the greater involvement of PLWHAs and other vulnerable groups in HIV and AIDS prevention, treatment, care and support initiatives will need to be able to argue that the benefits outweigh drawbacks and point to ways to overcome the drawbacks.

For more information on the Positive and Negative effects of GIPA in CBOs, see:

Meaningful involvement of people living with HIV/AIDS - positive and negative effects of involvement in community-based programs - Alliance/Horizon

[http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Conferences/Meaningful%20involvement%20of%20PLHA.pdf](http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Conferences/Meaningful%20involvement%20of%20PLHA.pdf)
Key obstacles to PLWHAs involvement in CBOs working on HIV/AIDS - Lessons drawn from Burkina Faso

Summary: Here are some selected key findings from the pilot phase PLWHAs study in Burkina Faso conducted by the Alliance and Horizons. The study shows the obstacles in the way of PLWHAs involvement.

- Most people still do not know their HIV status because they have no access to testing.
- Many PLWHAs do not join CBOs working on HIV/AIDS because they think that this will identify them as being HIV positive and they are afraid of stigma and discrimination. In fact, the vast majority of PLWHAs CBO members do not report discriminatory treatment as a result of their involvement.
- The lack of a referral system means that there is often little information about the services available and opportunities for PLWHAs to become involved in service delivery.
- Many PLWHAs expect something concrete from their involvement - for example, money, medication or food - which CBOs are usually unable to offer. Organisations need to find ways to support volunteers, for example by linking them to income generation projects.
- In countries where access to care is limited, PLWHAs sometimes join CBOs simply because they see this as a way to receive better care. They may not really want, or have the skills, to provide any services to the organisation.

Minimum Conditions for PLWHAs Involvement

At an individual level:
- Individuals need to know their serostatus.
- PLWHAs must want to become actively involved, with the initiative coming from the PLWHAs him/herself.
- PLWHAs require training and skills development to be effectively involved in service delivery.

At an organisational level:
- All CBO members have to believe that PLWHAs have the capacity to become actively involved in the organisation and to see a positive role for them in order to encourage the integration of PLWHAs within the organisation.
- CBOs must provide concrete information about the organisation and its services for PLWHAs.
- Psychological support should be available to PLWHAs who wish to be involved in CBOs.
- CBOs should encourage PLWHAs to carry out activities within the organisation, based upon their individual skills and strengths.
- CBOs have to be able to offer appropriate training to PLWHAs.
- CBOs have to be able to guarantee confidentiality and find ways for PLWHAs to become involved without necessarily revealing their status.
- CBOs have to be able to offer concrete benefits to their members, for example the opportunity to participate in income generation schemes.

At an institutional level:
- A legal framework must be in place to protect PLWHAs who decide to become involved.
- CBOs and PLWHAs should be involved in training health professionals and social workers to raise awareness of issues affecting PLWHAs.
- CBOs and PLWHAs should be involved to ensure that appropriate testing and counselling are widely accessible.
For more information on this issue, see:

Assessing Progress to Foster Greater PLHA Involvement in Burkina Faso (July 2002) Horizons research study
http://www.popcouncil.org/horizons/resum/plha4cntry/plha4cntry_bffollowup.html AND

Overcoming obstacles to the involvement of People Living with HIV/AIDS in community-based programs in developing countries - Alliance/Horizon
http://www.aidsalliance.org/ docs/ languages/ eng/ content/ 3_publications/download/Conferences/Overcomi ng%20Obstacles%20to%20PLHA%20Involvement.pdf

The Challenge of “Community”

As shown by the research above, the involvement of affected communities may be necessary but it will not be easy. Furthermore, there is difficulty in even defining the word “community” as most people who belong to affected communities may not identify themselves in this way, or may find it dangerous for them to do so.

Someone who identifies him or herself by a characteristic that is marginalised or stigmatised will be doing so on the basis of concepts of empowerment and community-building: for example, gay men and lesbians demand their rights by identifying themselves by their sexuality, and at the same time breaking down prejudices and stereotypes. Sex worker and drug user groups in some countries have followed the same model. However, even in these countries, it is a minority of these communities who will be willing to be active in a political way. In the same way, the vast majority of people from affected communities in the Asia-Pacific region will not want to identify themselves as a member of an affected community.

On a personal level, we choose to identify ourselves in many ways - by nationality, race, religion, profession. Drug users, PLWHAs, sex workers and men who have sex with men will probably not want to define themselves as such as they will be subjected to discrimination and harassment. Migrant populations would also not have a reason to adopt an identity based on their migrant status.

Our challenges therefore are many:

- We must work towards an environment where affected communities can identify themselves in this way - this will be discussed in the next chapter;
- As discussed above in the section on PLWHAs, where members of affected communities cannot represent themselves, mechanisms for incorporating their experiences and views must be developed;
- Likewise, where members of affected communities are unwilling to identify themselves, NGOs and CBOs must work to understand and reflect their experiences in their responses to AIDS;
- We must clarify and develop our use of the term “community”
  - so that it can be used in a specific enough way to create and facilitate effective responses to AIDS for all those who are affected by AIDS, and;
  - so that it is flexible enough to include the complex meanings and understandings of “community”, and the many communities which exist and that we belong to.
Chapter 2  A Human Rights Approach

This publication is about “community mobilization” because we know that effective responses to the HIV/AIDS pandemic happen when we, as affected communities - people living with HIV/AIDS, and people who are at risk of HIV infection - mobilize in collective action and take on the challenges ourselves to prevent HIV infection, and to ensure that people living with HIV/AIDS have access to appropriate treatment, care, and support services.

It is common to acknowledge that a “human rights approach” is necessary for an effective response to HIV/AIDS. This chapter looks at the interrelationship between human rights advocacy and community mobilization in responding to the HIV/AIDS epidemic.

One of the clearest expressions of what we mean by “community mobilization” is found in the Ottawa Charter for Health Promotion. It was written in 1988, at a time when few people had conceived of the magnitude of the impact HIV/AIDS would have on our world, but the principles it expresses are more relevant than ever as we fight to reduce the impact of the epidemic. The Ottawa Charter states in part:

*Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies, and implementing them to achieve better health.*

*At the heart of this process is the empowerment of communities - their ownership and control of their own endeavours and destinies.*

So what is the relationship between respect for human rights in the context of HIV/AIDS and community mobilization against the epidemic? What does it take to create an environment in which effective HIV/AIDS-related health promotion can take place? It requires respect for and promotion of the human rights of people living with HIV/AIDS, and of people who are vulnerable to HIV infection.

This chapter looks at what that means in practice, and attempts to articulate the advocacy agenda that we need to adopt if we are going to create the conditions in which communities can mobilize. “Mobilization” is not something we can “do” to people or communities. It is something for which we have to create the conditions in which people can do it for themselves. This is the message of “empowerment” that the Ottawa Charter expresses, and respect for and promotion of the human rights are central to it. It is not an esoteric concept: think about the rights you assume or assert in your daily life. What does it take for you to be able to live in the world, to be active and engaged, to take responsibility for your own well-being, or the well-being of your family and loved ones, to develop as a human being, and to enjoy life?

Because this publication is focused on community mobilization, we will look at communities affected by HIV/AIDS, and consider the impact that respect for or violation of the rights of members of those communities has on the course of the epidemic.
People living with HIV/AIDS

Often we hear HIV/AIDS-related human rights issues considered in the context of “vulnerable groups” or “vulnerable communities”, referring to HIV negative people who are at risk of contracting HIV. But the foremost consideration in taking a “human rights approach” to responding to the epidemic is ensuring that people living with HIV/AIDS are centrally involved in all aspects of the response. People living with HIV/AIDS come from all sectors of society, and are also members of all the other groups or communities who are vulnerable to HIV, whether they are men who have sex with men, or men who have sex with female sex workers, the women partners of these men, injecting drug users, or mobile populations. Think about how you draw up this list - it will vary depending on where you live, and the communities you live in and work with, but people living with HIV/AIDS are members of all communities, in all strata of society.

As well as being worthy of protection and promotion in their own right, the human rights of people living with HIV/AIDS also play a role in helping to contain the spread of the epidemic. This is illustrated by the fact that, except for the very small number of HIV transmissions which have taken place as a result of medical procedures, a person living with HIV/AIDS must be present for HIV transmission to occur.

Community mobilization is not something we “do” to people, it is something that we try to foster by creating the conditions in which it can take place. So what are the things that we need to work towards, if we are going to create the conditions where people living with HIV/AIDS can play a central role in the response to the epidemic?

Non-discrimination

In order for people living with HIV/AIDS to be able to mobilize, and to act publicly as people living with HIV/AIDS in the response to the epidemic, they need to be able to do so without risking their safety or livelihood, or that of the family and associates. That means that the society in which they live and act must take steps to counter HIV/AIDS related stigma and discrimination, and to provide sanctions against perpetrators, and remedies for people who are subject to discriminatory acts. In practice this requires political leadership in countering stigma, through public support for the human rights of people living with HIV/AIDS. It also requires laws prohibiting discriminatory acts against people or their families or associates which are based on peoples’ known or assumed HIV status, together with remedies for violations and sanctions against perpetrators. Ideally, there should be an institution such as a national human rights monitoring body charged with promoting and overseeing observance with human rights standards, including human rights in the context of HIV/AIDS.

Testing

People who may be at risk of HIV infection, or who may have been infected with HIV must have access to adequate HIV testing services. First of all, this is necessary for people living with HIV/AIDS to be able to identify their status. In a broader sense, this is also necessary to minimise the spread of HIV and to provide treatment,
care and support to PLWHAs. Only by having confidence in HIV testing services can people, monitor their HIV status, and seek appropriate treatment, care and support services as needed.

HIV testing services need to be accessible both geographically and in terms of their affordability. HIV/AIDS-related stigma and discrimination mean that people will not be able to access testing services unless they can be assured that their attendance at such services and any information about their HIV status or testing is kept confidential.

HIV testing must only be carried out with the voluntary informed consent of the person being tested. This means that the person needs to be provided with adequate pre-test counselling so that they will understand the meaning of the test results, and any obligations of the service performing the HIV test in relation to the test results. In many places, positive HIV test results must be notified to public health authorities, and this may include information which identifies the person who has been tested, or else information may be notified in non-identifying form. Some services are able to offer anonymous HIV testing, meaning that no information about the identity of the person who is being tested is retained.

The impact of stigma and discrimination on access to HIV testing services is that people will be fearful of accessing such services, in case they are assumed to be HIV positive, or else are assumed to be engaging in behaviour which can transmit HIV, such as injecting drug use or male-to-male sex. Stigma can also mean that less emphasis is placed on protecting the confidentiality of HIV-related information such as the fact that a person has sought an HIV test, or the results of an HIV test. Where stigma and discrimination are prevalent then there may be less motivation for and commitment to providing high quality pre- and post-test counselling, because the health of people living with or at risk of HIV infection is seen as less important in these circumstances.

Another impact of stigma and discrimination on the provision of HIV testing services is that the amount and quality of available epidemiological data can suffer. This can happen in a variety of ways. In some societies, behaviour which can transmit HIV is so stigmatised that information about particular risk behaviours is not even collected. An example of this is male-to-male sexual behaviour, which takes place almost everywhere in the world, but in many places is not included in the collection of HIV epidemiological data due to denial that male-to-male sex is taking place.

Confidentiality

A further measure that can promote the capacity of people living with HIV/AIDS to be public about their HIV status, is the right to control whether, and in what circumstances, information about their HIV status is disclosed. This can be achieved through laws and policies which promote and protect the right of confidentiality concerning HIV/AIDS-related information. The health sector is a key area where the confidentiality of HIV/AIDS-related information must be protected, because it is a sector where such information is likely to be disclosed. Health agencies which provide HIV/AIDS-related services, and other agencies they deal with, must have sound policies on protecting the confidentiality of HIV/AIDS-related information, and the staff of such agencies must be trained in the importance of observing confidentiality requirements. However the health sector is only one arena in which issues about HIV/AIDS-related information may arise. Other circumstances where the issue can arise include the workplace, educational institutions, and a range of service providers such as insurers and financial institutions.
In all of these areas, sound policies on the confidentiality of HIV/AIDS-related information need to be reinforced by laws which provide for a legal right of confidentiality, including compensation and other remedies for people whose rights have been breached, and sanctions against those responsible for breaches. Ideally, an institution such as a privacy commission, with legal powers to act against breaches of confidentiality, should be established and properly resourced, so that people living with HIV/AIDS know that there are steps they can take to obtain redress for breaches of confidentiality. The existence of laws protecting HIV/AIDS-related confidentiality, and providing remedies for breaches of the right to confidentiality, also function as a powerful educative tool, the impact of which is often as great or greater than the individual legal actions which people may take where their right to confidentiality has been breached.

**Access to treatment, care and support**

The right to life is a fundamental human right for all people. For people living with HIV/AIDS, enjoyment of the right to life means obtaining access to antiretroviral treatments, and to treatments for other health conditions associated with HIV infection. In many countries, communities of people living with HIV/AIDS have for years had to cope with the continual loss through AIDS-related deaths of community leaders, advocates, and others who have contributed to lessening the impact of the epidemic, through death from AIDS-related illnesses. Communities which bear such losses on a continuing basis will inevitably face enormous difficulties in “mobilizing” against the epidemic, and so access to treatments, and to appropriate care and support services, must be part of the advocacy agenda of any person or organisation which is committed to supporting the centrality of people living with HIV/AIDS in responses to the epidemic.

**Other human rights issues for people living with HIV/AIDS**

There are many other ways in which the social and legal environment can promote or undermine respect for human rights in the context of HIV/AIDS, and if we are committed to fighting the epidemic from a human rights-based approach, then our advocacy agenda has to incorporate these other human rights-related issues. There isn’t scope in this publication to examine all of these issues in detail, but the following is an overview of some of the most important issues:

**Criminal and public health laws**

Laws which create specific criminal offences for HIV transmission can undermine the effectiveness of public health measures, by contributing to the stigma associated with HIV/AIDS, and by conveying the message that HIV is spread intentionally by people who should be punished for their actions. Such an analysis is based on a flawed understanding both of human behaviour and of the capacity of the criminal justice system to control the transmission of HIV.

In the overwhelming majority of cases, HIV is spread through private and intimate behaviours such as consensual sex or drug use, or through circumstances over which people have no control, such as mother to child
transmission where the mother has contracted HIV from her husband. In many cases people may not know their HIV status because they don’t have access to HIV testing facilities. Where they are aware of their positive HIV status, people may not have access to the means of preventing HIV transmission such as sterile injecting equipment, or antiretroviral treatment for pregnant women.

In any case, the criminal law is inherently backward-looking, examining what has taken place and determining whether and how punishment should be imposed. We know from decades of experience in health promotion, and not only in the context of HIV/AIDS, that human behaviour, particularly where it concerns intimate and stigmatised behaviour such as sex or illicit drug use, is not shaped by an “information and punishment” model of intervention, but rather by empowering people to be able to take action to protect and promote the health of themselves and their loved ones.

In contrast with criminal laws, public health laws tend to be more forward-looking and focused on achieving future behaviour change, rather than on identifying and punishing those who have breached laws. There are often human rights issues that need to be addressed if public health laws are to play a constructive role in minimizing the impact of the HIV/AIDS epidemic. For example, public health laws will be more respectful of the rights of people living with HIV/AIDS when they operate on the basis that less intrusive interventions - such as behaviour change counselling - should be used to achieve the desired public health outcome, before consideration is given to interventions which are more intrusive, such as compulsory testing, or restrictions on individual liberty.

Two papers which are available on the internet, and which examine in detail the issues associated with the role of public health and criminal laws in containing the impact of the epidemic are:

- **Reforming the Law to Ensure Appropriate Responses to the Risk of Disease Transmission** - [www.ancahrd.org/pubs](www.ancahrd.org/pubs)

Other areas in where HIV/AIDS-related human rights violations may be manifested include prisons, where HIV positive prisoners may be forcibly tested for HIV, or segregated from the rest of the prison population, or denied access to facilities available to other prisoners. Medical research laws and protocols must provide for the ethical treatment of HIV positive people who take part in research on new HIV treatments, including ensuring that participation in clinical trials is subject to voluntary informed consent, the right to share in the benefits which result from such research, as well as ongoing access to treatment following the conclusion of any clinical trials of HIV treatments. Consumer protection laws must also ensure the enforcement of adequate standards of safety and efficacy for any products for the prevention of HIV transmission or the treatment of HIV infection.
Organisational and Workplace policies

At an organisational level, institutions which are committed to people living with HIV/AIDS being central to all aspects of their work, need to ensure that the conditions in which they function encourage PLWHAs involvement. This may mean that staff who are living with HIV/AIDS require access to more paid sick leave than non-HIV positive staff, and that there is a time-out room or rest space that HIV positive staff can use as needed during the working day. It may mean being sensitive to the scheduling of activities which particularly involve HIV positive staff - some people taking antiretroviral treatments experience more severe side effects from their medication at certain times of the day, and may not be able to function optimally in the workplace during these times. Some workplaces have established mechanisms for confidential consultations with HIV positive staff on issues which are particularly relevant to these staff.

Measures such as these will encourage the involvement of people living with HIV/AIDS in an organisation, but must be implemented in a way that remains respectful of the confidentiality of information about people's HIV status. Staff must be able to choose whether or not their HIV status will be known in the workplace, and whether or not they will participate in forums established specifically for HIV positive staff, or avail themselves of whatever additional entitlements an organisation establishes for HIV positive staff.

Sex Workers

The starting point for promoting conditions in which sex workers can mobilize to respond to HIV/AIDS, is Article 23 of the Universal Declaration of Human Rights. It states:

Everyone has the right to work, to free choice of employment, to just and favourable conditions of work, and to protection from unemployment.

Many of the violations of sex workers’ human rights, which occur in societies throughout the world, derive from the fact that sex work is not acknowledged as work, and consequently the industrial rights which are accorded to other workers are not seen as applying to sex workers. The violations of human rights which are manifested in the denial of basic industrial rights to sex workers, have direct consequences for sex workers’ vulnerability to HIV infection, and so our advocacy for conditions which will enable sex workers to mobilize against the HIV/AIDS epidemic will necessarily involve advocacy for industrial rights for sex workers.

What are these industrial rights that affect sex workers’ vulnerability to HIV infection? They include adequate occupational health and safety standards for sex industry premises, such as the provision of condoms and lubricant, sanitary working premises, adequate lighting, and ergonomically safe equipment. In addition, the law should not impose restrictions on sex workers and sex industry businesses that are more onerous than the restrictions placed on analogous personal service industries, such as non-sexual therapeutic massage services, physiotherapists, and allied health services.
Measures also need to be taken to address the stigma associated with sex work, and the discrimination that is often perpetrated against sex workers on the basis of their occupation. Decriminalisation of the sex industry can contribute to reducing the stigma which is associated with sex work. And if sex workers are going to be public actors in the fight against HIV/AIDS, then they need the protection of laws which prohibit discrimination on the basis of their occupation, as well as access to remedies for violation of these laws. There should also be sanctions against perpetrators of human rights violations against sex workers.

In many parts of the world, sex workers are subject to bonded or forced labour, and by various means are subject to trafficking either within or across national boundaries. Measures which aim to address these serious violations of sex workers’ human rights should not contribute to the further stigmatisation of sex workers by singling them out for special treatment, or by including punitive measures against those workers who are trafficked. Forced labour and the trafficking of human beings is both abhorrent and illegal in almost all societies. There are few countries where existing laws regulating the labour market cannot deal with issues of trafficking in forced labour of sex workers, and anti-trafficking laws which specifically target the sex industry risk adding to the stigma associated with sex work. It is through the recognition of the human rights of sex workers, and respect for their industrial rights, that sex workers will be empowered to, in the words of the Ottawa Charter, take “ownership and control of their own destinies”.

A common violation of sex workers’ human rights is the requirement of mandatory or compulsory testing for HIV and other sexually transmitted infections. Sex workers should be encouraged to have regular sexual health checks, and there is no evidence to suggest that where such services are offered in a manner that is respectful of sex workers’ autonomy and right to exercise control over their own health, that sex workers will not avail themselves of those services. But there is evidence to suggest that mandatory or compulsory testing of sex workers for HIV and other sexually transmitted infections is counterproductive to effective sexual health promotion”.

Similarly, legal and policy frameworks that require the registration of individual sex workers contribute to the stigmatisation of sex workers, create opportunities for corruption in the regulation of the industry - particularly in countries where the rule of law is not strong - and also impair the effectiveness of health promotion initiatives by and with sex workers by undermining sex worker autonomy.

Another commonly seen violation of sex workers’ human rights is the exclusion of sex workers with HIV from working even where adequate precautions - such as condom use - are taken to prevent the transmission of HIV and other sexually transmitted infections. At first glance there may seem to be a certain logic to such an approach, but it in fact both reflects and reinforces the stigma attached to sex work. This can be illustrated by comparing the approach taken to sex workers with HIV or a sexually transmitted infection with the approach taken to people in other forms of employment where there is a risk of blood-borne virus transmission.

Take the example of HIV positive health care workers, who in most parts of the world are not prevented from continuing to work in their chosen field of employment provided they take appropriate infection control precautions. There is a tiny percentage of health care workers who are prevented by blood-borne virus infection
from continuing their work, and these are people who perform “exposure prone procedures”. “Exposure prone procedures” are a small subset of surgical procedures in which the health care worker is required to perform surgery in poorly visualized sites - places where they can’t actually see what they are doing, such as some forms of dental surgery. Apart from this very small subset of health care workers, the approach most widely adopted is to ensure that the health care worker with a blood borne virus is aware of and implements the correct infection control procedures. There is no reason why the same approach should not be adopted in relation to sex workers, except that in most cases the stigma attached to sex work, and the low status and mistrust of sex workers means that exclusion from the industry is more likely to be seen as the appropriate action to take. Proponents of excluding HIV positive sex workers from working also assume that all sexual acts involve a risk of HIV transmission from an HIV positive sex worker to a client, whereas in many cases the sexual services provided by sex workers carry no risk of HIV transmission.

Other violations of the human rights of sex workers include, in societies where sex work is illegal, the use by police of sex workers’ possession of safe sex equipment such as condoms and lubricant as evidence of the commission of criminal offences, and the culture of impunity in which many law enforcement officials operate regarding the sex industry.

Even where sex work is legal, the stigma attached to sex work, and the low status of sex workers, mean that police can act in defiance of the law in their dealings with sex workers. Many such instances have been documented, including in Cambodia, where a report by the Cambodian Women’s Development Association and the Cambodian Prostitutes Union found that women working in the Tuol Kork district of Phnom Penh are continuously subjected to human rights violations by police, including illegal arrests, beatings, extortion, and rape[71]. The report found that 72 percent of sex workers surveyed said they had experienced a human rights violation by police, and these included arbitrary arrest, denial of the right to work, beating with sticks and guns, rape, forced labour, and extortion.

The Cambodian Women’s Development Association called for urgent action including training for police officers that focuses on the human rights of women, and criminal proceedings against police who misuse their authority to violate sex workers’ human rights.

Creating the conditions which promote the ability of sex workers to mobilize against HIV/AIDS means advocating for the redress of these human rights violations, and an important programmatic element of enhancing respect for the human rights of sex workers is to involve police and other law enforcement personnel in education and awareness raising of HIV/AIDS as a public health issue.

**Men who have sex with men**

There are some particular challenges we face in developing effective HIV/AIDS health promotion policies and programs targeting men who have sex with men, and the question of how to take a human rights approach, and what sort of community mobilization can be expected in any given cultural context, is a complex one. One of the challenges we face is that in many countries the degree of stigma, discrimination and denial concerning male to male sex is such that information on male to male sex as a risk factor in HIV transmission is not even collected.
UNAIDS estimates that somewhere between five and 10 percent of HIV infections worldwide are the result of sex between men\(^27\). Irregular sentinel testing in some countries has produced some data. An article published in January 2003 in the Journal of Acquired Immune Deficiency Syndromes\(^27\) pulled together the following data on AIDS cases where male to male sex was identified as a risk factor:

- **Singapore** - 29%
- **Philippines** - 33%
- **Hong Kong** - 32%
- **Indonesia** - 15%

The same article reported that HIV prevalence among men who have sex with men in Cambodia was 15% in 2000, and that the only known data from Vietnam indicated HIV prevalence of 5.8% among 208 MSM who presented at a voluntary testing centre in Ho Chi Minh City in 2000.

So one of the challenges for HIV prevention and health promotion initiatives for MSM is that due to the level of stigma and denial, there often isn’t a lot of epidemiological data available to inform policy and program development. Another challenge is that the meanings which attach to male to male sex are very culturally specific, and this has consequences for approaches which aim to promote “community mobilization”.

In many Western countries we have seen the development and mobilization of communities which have formed on the basis of sexual orientation, such as gay communities in the United States, Australia, and Europe. In some countries in Southeast Asia, organisations have formed which identify more or less openly as gay and work in HIV prevention and health promotion, such as Pink Triangle in Malaysia, and the Library Foundation in the Philippines. However, these seem to be the exception.

Taking the example of South Asia, an article published by the NAZ Foundation International\(^28\) identified at least five different “behavioural dynamics” or categories into which male-to-male sex in South Asia falls. The author considered that only one of these categories is what in Western countries would be recognized as gay identified males, who in South Asia are said to inhabit “small, English speaking, educated male networks”. The article concluded that only one other category of male to male sex gave rise to any sense of shared identity or potential for community development.

Notwithstanding these complexities, some fundamental principles of health promotion in the context of HIV/AIDS remain valid wherever men are having sex with men - which is everywhere - and they need to inform our human rights advocacy agenda if we are going to promote community mobilization to reduce the impact of the epidemic.

Regardless of the cultural meanings which attach to sex between men, we know that stigmatisation and discrimination towards target populations impair the effectiveness of health promotion initiatives by and with those populations, and so we need to advocate for the reform of laws and policies which stigmatise or discriminate against men who have sex with men. These include laws which criminalize sex between men, or provide for a higher age of consent for sex between men than for sex between men and women. As with other

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27 AIDS and men who have sex with men - UNAIDS technical update May2000.
people who are vulnerable to HIV infection, and come from stigmatised populations, in order to be able to mobilize in response to the epidemic, men who have sex with men need the protection of laws and policies which prohibit discrimination against them because of their sexual behaviour, which provide redress for human rights violations, and which provide sanctions against the perpetrators of such violations.

Censorship

In some cases, the discriminatory application of censorship laws is a mechanism by which the right to health of men who have sex with men is violated. Effective sexual health promotion requires the production of information and education materials which are sufficiently explicit to get their message across to their target population. In the case of men who have sex with men, this means that IEC materials will sometimes need to contain explicit depictions and descriptions of sex between men, so that meaningful information about HIV prevention and sexual health promotion can be conveyed. However, in societies where sex between men is illegal, or stigmatised, it is not uncommon for health promotion resources to be used as evidence of criminal offences by those involved in HIV prevention and health promotion. Hence, one part of our advocacy agenda for a human rights approach to fighting the HIV/AIDS epidemic involves challenging laws or discriminatory practices which prevent the implementation of effective health promotion initiatives.

A graphic example of the role that human rights violations can play in impeding the effectiveness of HIV prevention and health promotion for men who have sex with men was seen in Lucknow, India, in 2001, where police accused staff of Bharosa Trust and Naz Foundation International, who were involved in HIV prevention outreach work with men who have sex with men, of running a “sex racket”, and of showing pornographic films in their offices. These charges were eventually dropped, although workers were imprisoned for 47 days, part of that time without access to potable water, clean food, or sanitation facilities. Organisations working with MSM reported that attendance at support group meetings dropped, and vulnerable men were harder to reach for AIDS prevention work, as word of police harassment spread and many men feared similar abuse.10

Other HIV and health promotion organisations around the world have been subject to varying degrees of harassment by censorship or law enforcement officials for the IEC materials they have produced, and the accusation of “pornographer” is one that has been made many times. Other accusations might be that by providing MSM with safe sex information you are “recruiting” men to homosexuality, and if your community development work involves establishing safe spaces where MSM can meet then you’ll probably be accused of running a “dating agency”. Don’t be put off by these kinds of criticisms. HIV health promotion is about saving lives, and if you target your activities properly, then the only people you’re going to offend are people who are looking for opportunities to attack you.

Injecting drug users

A good starting point for understanding a human rights approach to HIV/AIDS and injecting drug use is Article 12 of the International Covenant on Economic, Social and Cultural Rights, which states:

*Everyone has the right to the enjoyment of the highest attainable standard of physical and mental health.*
In many societies injecting drug use is the most stigmatised of all the behaviours that can transmit HIV, and an additional challenge is that there are usually conflicting legal, policy, and programmatic responses by different arms of the state, depending on whether the relevant agency regards drug use as a health or a law enforcement issue. It is a complex environment in which to pursue a human rights agenda, but the same health promotion principles of community empowerment, and people’s ownership and control of their own health, apply.

Health promotion in the context of injecting drug use is often conceived of narrowly, and seen as requiring only a supply of sterile injecting equipment, and while it is true that this is important for the health of injecting drug users, drug users have other needs which also form part of their right to health. Other components of the right to health for injecting drug users include peer education programs and IEC materials, the provision of safe places in which to inject, and access to treatment for drug addiction.

As with other illegal behaviours, the police play a crucial role in determining whether illicit drug-related health promotion initiatives will be permitted to operate effectively, or whether law enforcement activities will impede or prevent their operation. Promoting respect for human rights in the context of illicit drug use will necessarily involve working with police - both new recruits and serving officers - to increase their awareness and understanding of the importance of health promotion in the context of illicit drug use. The preservation of human life should be a law enforcement priority, and where the actions of police contribute to the burden of drug-related harm, then there is a clear need to advocate for changes to law enforcement activities.

How do you know when you are doing it?

In summary, how do you know when you’re taking a “human rights approach” to HIV/AIDS? And how do you know that your advocacy agenda is going to promote mobilization by communities of people living with or vulnerable to HIV/AIDS?

Here are a couple of checklists you can refer to:

- The Ottawa Charter for Health Promotion: read it! It was written last century, but it remains one of the most powerful explanations of the meaning and importance of community advocacy, mobilization and empowerment, in achieving the right to health.

  [http://www.who.int/hpr/archive/docs/ottawa.html](http://www.who.int/hpr/archive/docs/ottawa.html)

- The International Guidelines on HIV/AIDS and Human Rights: although aimed at influencing the actions of governments, the guidelines provide a clear agenda for advocacy organisations which aim to promote community mobilization in response to HIV/AIDS.

  [www.unaids.org/humanrights](http://www.unaids.org/humanrights)
Chapter 3  Building capacity and involving community

In Chapter 1, we proposed that the involvement of affected communities in a response to HIV and AIDS is necessary to make that response effective. Prevention, treatment, care and support initiatives must be shaped by the lived experience of vulnerable communities and people living with HIV/AIDS.

The means to involving necessary communities and individuals is often through Community-Based Organisations (CBOs) and Non-Governmental Organisations (NGOs) that represent vulnerable and marginalized populations and people living with HIV and AIDS (PLWHAs). This chapter will discuss capacity-building among CBOs and NGOs and feature case studies which demonstrate how organisations and individuals have become empowered or empower others to better respond to the HIV epidemic.

The case-studies will focus on different marginalized communities as well as examining general capacity-building efforts among NGOs and CBOs. An effort has been made to focus on the key marginalized populations described in chapter 1. At the same time, short conclusions interspersed with the case studies describe common themes and links between them.

The case study approach

A case study is a story or narrative. In this publication, it is generally a description about how people implemented a certain activity or program.

- **A good case study:**
  - Focuses on people rather than chronological events
  - Focuses on the question of “how” as well as “why?”
  - Reflects on and analyses how people come to understand things, decide to do something, how they get things done and learn through doing
  - Reflects the complexities and contradictions of real life
  - Offers a way of understanding an experience

A case study is not a formula to follow or a set of rules. Instead, it should illuminate something about the subject that it is being applied to. Hopefully then, the reader will gain an awareness of different issues and processes, and can draw from a case study the interpretations, insights, lessons and conclusions that are relevant to their own interests and work.

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31 This section draws on the work of Elizabeth Reid in preparatory notes for the International Roundtable on Increasing Access to HIV Treatment In Resource Poor Settings called “A Note on Case Studies”. It can be found at: http://rspas.anu.edu.au/hiv/downloads/orgdocs/methodology.pdf

32 Wittgenstein, a European philosopher, in describing a case study approach, uses a metaphor of the story teller as a guide: “I’m like a guide showing you how to find your way round London. I have to take you through the city from north to south, from east to west, from Euston to the embankment and from Piccadilly to the Marble Arch. After I have taken you many journeys through the city, in all sort of directions, we shall have passed through any given street a number of times - each time traversing the street as part of a different journey. At the end of this you will know London; you will be able to find your way about like a born Londoner. Of course, a good guide will take you through the more important streets more often than he takes you down side streets; a bad guide will do the opposite.”
This chapter presents case studies that promote the aims of this publication:

To foster advocacy by communities affected by the HIV/AIDS pandemic, and to promote the involvement of marginalised communities, including PLWHAs, in the response to HIV/AIDS at the local, national, regional and global level.

The case studies have been drawn from a variety of sources including newspaper reports, internet postings and direct contact with individuals and organisations. They are all stories about how certain people, groups or institutions have set out to do something about responding to HIV/AIDS and involving affected and marginalized communities. They are also stories in progress and are incomplete. If we return to them in six months or a year, key messages or outcomes may have changed. But hopefully, they are studies of processes where the desire to do something led to something being done and where those involved learnt while doing, and incorporated those lessons back into what they were doing to make it better.

A key question is: how did it come about that this particular person, group or organisation started to work on these issues? The answer will usually be in terms of people who saw a need and chose to do something - social actors, visionaries, change agents, or simply people who are dedicated to an issue. A person or a group of people, inside an organisation or outside of it, were committed to doing something to improve the situation. They were trying to change the status quo. How did they go about it? Were there losers? What were the embedded power relations in the status quo? How did they convince others to share their goal/dream? The triggers for change may often be almost intangible: a way of doing things rather than what is being done or argued.

**PLWHAS case study**

**Case Study: The Benefits from Involving Positive Men in Gay Men’s Prevention Campaigns**

Summary: It is not just decision-makers outside of our organisations who need to promote the involvement of affected communities in responding to HIV/AIDS. This example shows how HIV/AIDS educators working with gay men needed to and were successful in involving an affected community, positive gay men.

HIV prevention campaigns for gay men in North America, Western Europe and Australia began with the concept of an infected population and an uninfected population. The aims of campaigns were to prevent HIV negative men from sero-converting, and thus the focus of education campaigns was on using safe sex supplies such as condoms and lubricant. The focus for positive men was on the provision of adequate treatment, care, and support.

Australia was one of the first countries to champion the involvement of positive men in prevention campaigns. Why? HIV transmission takes place between a positive person and an uninfected person. Therefore, it makes sense to include positive men in campaigns. If all efforts are focused on HIV negative men, it effectively leaves out half of the equation. By including HIV positive men in prevention campaigns, it also assumes these men will not want to infect their negative partners, and with support and information, will develop strategies to protect them.
New HIV prevention campaigns were designed that specifically aimed at positive men, looking at issues of self-esteem, health, and other issues. But prevention campaigns also incorporated the viewpoints of positive men. Who better to help understand the factors that may increase HIV infection than those who are themselves infected?

Much of the impetus for this change came from HIV positive men themselves. The Australian response to HIV/AIDS has been characterised by strong involvement by affected communities, in particular, gay men and HIV positive gay men. Early in the epidemic, people with HIV coined the phrase "talk with us, not about us". The principle was advocated that people living with HIV and AIDS where possible "represent ourselves, and speak for ourselves: to government, in clinical research, or around any other table where significant decisions affecting our lives and health are likely to be taken."

In practice, this took many forms. Both at the national and state level, HIV positive men were employed specifically to run programs for HIV positive men. In addition, different methods were used to further receive input from other positive men, whether through PLWHAs organisations at national or state levels, or through consultations and focus groups. Positive men willingly participated in research about safe sex practises and the effects of HIV/AIDS on their lives.

A similar change in focus has happened in gay men’s prevention campaigns around the world. In this case, the affected community that needed to be involved was HIV positive gay men, and the group of people that needed to facilitate that happening were gay men’s educators. By doing so, responsibility for preventing new HIV infections becomes shared between all gay men, positive and negative, and the effectiveness of campaigns has likely increased as well. Involvement by affected communities has been shown through HIV positive men being central to the planning and implementation of these programs.

**Conclusions: PLWHAS case study**

While Australia’s response to HIV/AIDS is different than in many other parts of the region, this case study shows an example of why involvement of an affected community was needed, and the necessary shift in thinking that allowed this to happen.

The benefits from involving PLWHAs occur at two levels. On the individual basis, it helps to empower PLWHAs and develop their capacity and skills. At an institutional level, it informs the work of organisations so that prevention, care and treatment initiatives are informed by the experiences of those who the programs are directed at. At a governmental level, the centrality of positive people in a response to HIV improves education and policy responses by developing a partnership approach where all stakeholders work together in a positive way.

These benefits can be seen to apply more generally to the whole concept of involving affected communities in responses to HIV and AIDS. By doing so, it can help community representatives and organisations to develop advocacy abilities. And for responding to HIV, whether it be at a national, regional and international level, and
whether it be through a conference, a report or an intervention for prevention, or care and treatment, the response is better informed by those who are infected and affected by HIV/AIDS.

As discussed in Chapter 2, as well as in the Horizon research findings in chapter 1, it may be necessary to provide a supportive environment for PLWHAs to facilitate their involvement in other parts of the region. A comprehensive approach to HIV/AIDS is needed that advocates for national frameworks that include testing and counselling and legal protection for PLWHAs at the same time as considering organisational issues such as whether appropriate resources for training and support are available, and whether policies on issues such as confidentiality have been developed.

The involvement of people living with HIV and AIDS in the global response to AIDS is the key reason for organisations such as the Global Network of People Living with HIV/AIDS (GNP+) and the Asia Pacific Network of PLWHAs (APN+). This task has proved to be a difficult one. PLWHAs should be involved in not only programs and campaigns such as described above, but should also be sufficiently represented in global and regional making decision-making processes, conferences and bodies.

**Intravenous Drug User (IDU) Case Studies**

Intravenous Drug Use is one of the main methods of transmission of HIV in the Asia Pacific region, specifically in countries such as Nepal, Vietnam and Thailand. However, drug use is generally illegal and highly stigmatised. Drug users themselves face harassment by the police, discrimination, and lack of health and social services. This has meant that the development of organisations to advocate on IDU issues has been slow in many countries. Following the principle discussed in the case studies on PLWHAs involvement, that is, the involvement of affected communities in the response, a key concern for organisations that deal with the issue of illicit drugs is the involvement of drug users themselves.

The following short case studies, all supplied by the World Health Organisation, examine these issues, and demonstrate the ways in which drug users are organizing and becoming involved in prevention and care programs.

In addition to these case studies, the Regional Task Force on Drug Use and HIV Vulnerability has just published a book of case studies called “Preventing HIV/AIDS among drug users: Case Studies from Asia.” The collection includes case studies on a multi-country community-based intervention and drug demand reduction and HIV prevention, a care and support program in Manipur, Outreach in Dhaka and Pakistan, and with street children in Cambodia, and substitution therapy in Bangkok and Hong Kong. Copies can be obtained through UNAIDS at unaids-seapict.unescap@un.org.
Involving Drug Users in Outreach Programs in Nepal

Summary: This case study, supplied by the World Health Organisation, describes the successful outreach work of an organisation in Kathmandu that involves ex drug users. The program also utilizes active drug users to disseminate information, reach new clients and work in new areas. Needle-sharing has decreased, and education on safe-injecting has reached hundreds of active users.

Lifesaving and Lifegiving Society (LALS), a local non-governmental organisation in Nepal, started outreach among injecting drug users in Kathmandu in 1991. How did they reach IDUs? First, it was necessary to involve affected communities - former or current IDUs. By doing this, the outreach program had better knowledge of where IDUs congregated, their needs, and how to communicate with them.

However, the program needed to employ additional people. In a 1999 report, LALS managers noted that outreach in Kathmandu was best achieved through a mixed group of paid staff and active IDUs: “LALS is often not able to rely on peer educators to deliver all the HIV education/ prevention and harm reduction supplies (needles, syringes, swabs, bleach, condoms).” So the regular delivery of education and supplies is done by outreach workers, with active IDUs assisting in extending messages and supplies to new areas and new clients whenever they can. This shows that the program tried to recognise the particular strengths and expertise of their IDU workers compared to the other workers.

In this program, ten community health outreach workers were employed to visit 64 sites in Kathmandu and neighbouring Lalitpur on a regular basis to visit the homes (temporary or permanent) of IDUs, and the places where IDUs congregate. The outreach workers included ex drug users, nurses and social workers, all of whom were trained together in outreach methods and in the skills and knowledge needed to educate IDUs about HIV/AIDS and injecting drug use. Outreach workers provided education and counselling (including sexual counselling with clients and their sex partners), and distributed needles and syringes, condoms, swabs and medications for minor ailments. They also provided treatment for abscesses and other first aid.

Using this system, the outreach workers reached 1200 IDUs by 1998. The number of times injecting equipment was shared by IDUs reached by the outreach workers fell from 14 times per week in 1991 to 7 times per week or less in 1993 and 1994. The longer clients stayed in the program, the less sharing they reported.

Lifesaving and Lifegiving Society also involved IDUs in peer education work. LALS provided group education to IDUs (all of whom were clients reached by outreach workers) to spread HIV prevention messages to networks of IDUs throughout the city and Kathmandu Valley. In 1998, a total of 391 IDUs attended 21 training sessions on topics including counselling, HIV/AIDS peer education, bleach use, hepatitis, safer sex and drug related harm. Bleach (to disinfect needles and syringes), sterile water, condoms and educational materials were provided to IDUs who attended these group education sessions to pass on to their friends and acquaintances.
Sources:
- Singh M and Shamsuddin M 1999
- Reflection of three years: progress report of LALS April 1996 to September 1999. LALS. Kathmandu
- Peak A, Rana S, Maharjan SH, Jolley D and Crofts N. 1995

Outreach methods - Video by IDUs for IDUs - Australia

Summary: This case-study, supplied by the World Health Organisation, describes a project that reaches out to young drug injectors, trains them in basic elements of video production and peer education and in doing so, encourages them to learn and reflect on their own drug use and that of their peers.

PEIRS - Peer Education and Information Reaching the Streets - is a project by VIVAIDS, an injecting drug users group in Melbourne, Victoria. It seeks out young heroin injecting young people who buy their drugs from open, street-based markets, and trains these IDUs in basic elements of video production and peer education. The drug users visit various services and learn about the risks of buying heroin from street markets, risks of injecting, overdose and other issues relevant for drug users. They then make a video, based on their experiences and what they have learned.

VIVAIDS says: “Through the peer education process and the development of peer education resources, they will be learning how to address their own drug use issues and the issues of drug use amongst their peers.”

Outreach: Working with IDUs to reach IDUs in Dhaka

Summary: This case-study, supplied by the World Health Organisation, describes outreach work to injecting drug users. The initial rapid situation assessment involved active drug users as guides. The project trained active drug users as peer educators and within a year increased its services ten-fold.

An outreach program, the SHAKTI Project, was started in Dhaka, Bangladesh in May 1988 by the international non-governmental organisation, CARE. Before starting the project, a rapid situation assessment was carried out, using the World Health Organisation Rapid Assessment and Response Guide for Injecting Drug Use.

This assessment estimated that there were about 7650 drug injectors and at least 11,000 heroin smokers in Dhaka. It found (among other information) that over 80% of IDUs had shared needles and syringes while 90% had shared other injecting equipment; that the sexual partners of IDUs were most often also IDUs; that 30% of IDUs were homeless, and 46% had no education. Project staff, with the help of guides (who were active IDUs) and other key informants, mapped the city through extensive field visits and observations, identifying 42 drug injecting places in Dhaka, some of which were also drug selling places. This information was provided in a “debriefing” in May 1998 attended by representatives from governmental, non-governmental and international organisations, members of the local community and IDUs.
The project began by training 12 active IDUs to become outreach peer educators. The training lasted five days and covered a range of topics, including education of other IDUs on STDs/HIV/AIDS, drug related issues and offering health services for abscesses and STDs, exchange of needles and syringes and distribution of condoms. During the training, rules for staff behaviour were developed (such as no injecting while working; no carrying of drugs during work hours; and avoiding involvement in criminal activities), and working hours were agreed with staff.

In June 1998, SHAKTI outreach workers managed to reach and educate 150 IDUs, and gave out 1753 syringes. At that time the project had one drop-in centre, 12 outreach peer educators and no volunteer peer educators. Through a process of constant expansion, of opening new drop-in centres, training volunteers peer educators, the SHAKTI team was able to reach more than 10 times as many IDUs a year later. By June 1999, the average number of IDUs reached each day was 1945, reaching over 2200 on some days. A further six drop-in centres had opened; there were 26 outreach peer educators trained; 160 volunteer peer educators and 20 medicine shop sellers trained. In that month, the project distributed 16,213 and 50,000 needles and syringes.

**Source:**


**Conclusions: IDU Case Studies**

These success stories of HIV/AIDS and illicit drug use offer many lessons. Just as involving PLWHAs in CBOs will improve the ways that CBOs deal with HIV/AIDS through the lived experiences of PLWHAs, the involvement of former or active drug users in HIV prevention and care programs aimed at drug users offers similar benefits. Users understand the issues surrounding the use of illicit drugs. They will be able to identify the best locations for outreach. They will be able to talk directly with other users with a personal understanding of their situations and circumstances.

The case studies describe the improvement of prevention and outreach through the involvement of affected communities. Needle-sharing in IDUs reached by LALS decreased considerably. The number of clients using the services of SHAKTI rose considerably.

These stories also describe a situation where the messages may be more acceptable to the people who need information or treatment because they are delivered by those who have credibility. The outreach workers have shared experiences. Principles of peer education, such as this, are important to integrate into responses to HIV and AIDS. Affected communities must drive these responses.

The example from Bangladesh indicated success in identifying a need and responding to it. Responses to HIV/AIDS must be grounded in the realities of affected communities and the lesson is clear: See what people need. Respond to those needs.
At the same time, the case study on LALS showed the organisation using active IDUs in combination with other outreach workers. A partnership approach is necessary where affected and vulnerable communities work with others. The experiences of affected communities are made central within a framework of collaboration.

The examples from Nepal and Bangladesh both show a recognition of weaknesses and strengths of using affected communities and developed strategies accordingly. LALS recognised that they could not rely only on IDUs for delivering supplies and that a particular strength of IDUs was in reaching new clientele. SHAKTI recognised the need to develop rules and guidelines with IDUs to facilitate their work.

All three programs recognised that you cannot simply “involve” affected communities but must give them training, skills and opportunity.

**Sex Worker Case Study**

Sex workers are marginalized and stigmatised due to many factors including their work, class, gender and sexuality. Society often morally disapproves of sex work, and furthermore, actively and passively discriminates against sex workers with legislative frameworks that control their lives and work, or do not protect them from discrimination and violence. Dr Smarajit Jana and his colleagues noted in an article in *Research for Sex Work* that, “sex workers are vulnerable to HIV transmission, not just because of their sex lives, but because they are not in a position to take decisions to protect their health and their life.”

Therefore, before sex workers can be included in decision and policy-making, sex workers as a group and a community will need to be able to participate in society in general. They will need access to resources, and to be empowered to respond to HIV and AIDS and protect themselves through HIV prevention programs, and be included in decision and policy-making.

**Summary:** The following case-study, on the famous Sonagachi project in India, comes from an article for the New York Times as well as an academic paper for the Journal of Sex Work. It is this chapter’s longest case-study because it provides such an inspiring example of how vulnerable groups can not only be involved, but can be empowered to be leaders in the response to HIV and AIDS.

**Sonagachi AIDS Project: Kolkata, India**

The Sonagachi AIDS Project in Kolkata, India, has gone from being a quasi-governmental program to one of the largest community-run intervention projects in the world. Sex workers are now in charge and in the Sonagachi red-light district in the city, only 9 percent of about 6,000 sex workers are HIV-positive. In comparison, rates of infection among Mumbai (formerly Bombay) sex workers as of 1997 were as high as 70 percent.

Dr Smarajit Jana comments: “At national and international meetings on HIV/AIDS, we are often asked what it is that makes the Sonagachi Project work? Our usual one-line rejoinder is, “responding to the targeted community’s needs”. The simplicity of our answer tends to disappoint the inquirer who expects us to present a complicated,
intricate model. We try to be helpful and go on to explain that “an intervention becomes effective only if it creates an enabling environment for members of the target community to act on their own behalf and in their own interests”.

The Sonagachi Project was started in 1992, spearheaded by Dr. Jana, a governmental epidemiologist, primarily as an operational research project to assess the prevalence of STDs and HIV among sex workers in the red light districts in and around Sonagachi in Calcutta, India. The research involved mapping the practice of sexual behaviour among sex workers, their clients and partners, and estimating the prevalence of STDs and HIV among them.

After these preliminary surveys, an intervention programme was started in the area with the objective of controlling the spread of STDs and HIV among sex workers and their partners and clients. The intervention programme started with three principal components: providing health services including STD treatment from a central clinic in the area, dissemination of IEC messages regarding prevention of STD/HIV transmission; and promotion of condom use.

For implementing the outreach components, a group of sex workers from the locality were employed as peer educators. Jana convinced 12 sex workers to come forward and train as “peer educators.” For about a $1 a day, and wearing green cotton coats, these women informed their “sisters” about STDs, urged them to get the clinic-provided blood tests every three months, and distributed condoms. This work could be seen to be enhancing self-esteem as a start to changing deeply entrenched sexual practices.

Soon, hundreds of women were refusing unprotected sex, even if their clients offered to pay more. While in 1992 a government survey showed a mere 2.7 percent of 450 sex workers were using condoms, two years later that figure had leaped to 69.3 percent, said Mrinal Kanti Dutta, present director of the sex workers’ union and the son of a sex worker.

“When a customer comes, I take the money first and then let him in my room,” said Priya Begum, a 23-year-old Sonagachi sex worker who had never heard of AIDS until a peer educator enlightened her last year. “Then I ask whether he’ll use a condom. If he says no, I keep the money and show him out,” she laughed. This is a tactic made more feasible by the cooperation of pimps, who have in most cases, agreed to back the women’s demands for safe sex.

Jana also emphasizes the success of the program though “a very flexible approach” adopted right at the beginning so that the programme could be adapted to changing circumstances and the needs articulated by the communities where they worked. “In this way we could remodel it when necessary, as our perceptions were enriched by our growing experience of working with the sex workers’ community.”

33 In the context of the Sonagachi Project this community refers to sex workers, that is anyone who has ever practised sex work as a profession and identifies herself/himself or is identified as a sex worker; their children; and their babus or regular clients.
Guiding principles of the Sonagachi Model

In order to successfully implement their programme, the Sonagachi Project aimed at creating an “enabling environment”, in other words, preparing and contributing to a situation that supports rather than obstructs their work. To do this, the Sonagachi Project established some basic guiding principles:

- From the very beginning there was no attempt to ‘rescue’ or ‘rehabilitate’ sex workers. They were accepted for what they were and their capabilities as human beings and workers were recognized and respected. The basic approach of the Sonagachi Project is summed up as the three ‘R’s: Respect, Reliance and Recognition - to respect sex work and persons engaged in sex work, to rely on them to run the programme and to recognize their professional and human rights.

- In the Sonagachi Project sex workers were not treated as passive ‘beneficiaries’ without any choice or agency but as change agents.

- In the early stages of the Sonagachi Project, peer educators, well supported by the programme management, recognized that in order to realize even the very basic programme objectives of controlling transmission of HIV and STDs, it was crucial to view sex workers as complete persons with a range of emotional and material needs and not merely in terms of their sexual behaviour. This holds true for sex workers but also applies to other target communities marginalized either because of their social exclusion per se or as a result of their vulnerability to HIV. The crucial first step in implementing any intervention programme for members of any marginalized population is to understand and address the range of issues that determine the quality of their lives and to locate these issues in the more general environment they are part of.

- In the Sonagachi Project, sex workers’ needs and interests were given prime importance in designing and carrying out any activity. The effectiveness and sustainability of any intervention programme depends on how far the community for whom the programme is implemented accepts it as beneficial to them. Thus, the programme must take into account and build on what the targeted community perceives as their immediate and urgent needs.

- The Sonagachi Project strongly emphasized the genuine representation and active participation of the sex workers at every level of the programme. Sex workers were given a central status within the programme right from the beginning. The leadership tried to imbue a genuine spirit of partnership between the project team and the community of sex workers they worked with. The authentic and dynamic involvement of members of the target community to carry out the programme (as opposed to the traditional approach of treating them as passive recipients of benefits) was crucial for ensuring effectiveness and sustainability.
Principal components
The guiding principles were translated into practice through three principal activity components:

1. **Working with the community**

The principles

- Safe spaces, both within the project and outside must be created for the members of the marginal community where they can confidently articulate their needs and hopes.
- A marginal, socially excluded and discursively invisible community has to be made visible.
- Steps have to be taken to facilitate self-actualisation of the members of the community.

*What the Sonagachi Project did*

- A relationship of trust was developed between the programme management and the sex workers’ community through involving them in all aspects of planning and implementation of programme components.
- Activities that directly addressed the needs articulated by sex workers were undertaken, even if they were not necessarily planned as part of the original proposed programme. Activities like literacy training and legal literacy training for sex workers were taken up. Immunization and other support services for sex workers’ children were also undertaken, like out-of-school education, sports, painting, cultural training etc.
- Their contribution to the programme and their role as members of the labour force were highlighted at local, national and international forums, thereby making them more and more visible as legitimate citizens, to inculcate a sense of pride and worthiness in them as sex workers.
- Steps were taken against all forms of discriminatory practices against sex workers, within the sex trade (like police harassment, violence, oppression by madams etc.) and outside it (exclusion of their children from mainstream education, social stigma against sex workers etc.).
- Any activity (e.g., on-the-job training and special capacity building sessions for sex workers) undertaken by the intervention programme proved to increase the capacity of sex workers. This also increased their self-esteem and empowered them socially, economically (by helping them to form their own credit society and social marketing agency), and politically (by facilitating the sex workers to combine and assert their rights and to help the formation of an exclusive platform of sex workers).
2. Working with the controllers of the sex trade

The principle

The hostility and the potential threat posed by controllers of the sex trade has to be neutralised through dialogue, negotiation and manoeuvring, so that the controllers do not impede the activities of the intervention programme.

What the Sonagachi Project did

- Sex work was accepted as a valid profession and no attempt was made at discouraging sex workers to practice prostitution and or at rescuing or rehabilitating them. This reassured the other stakeholders in the sex trade that outsiders were not going to disrupt their business.
- A thorough understanding of the sex trade, including the particularities of each red light area was developed to map the relation of power and conflicts in interests between different groups of stakeholders in the sex industry. Based on this understanding, specific strategies of manoeuvring were evolved and followed to win friends and neutralize enemies within the sex trade.
- Special activities were targeted at different sections of the controllers of the sex trade. These included madams, pimps, babus or regular clients of sex workers, to orient them regarding risk of transmission of STDs and HIV and also about the larger programme objectives to encourage them to work with rather than pose obstacles for the project.

3. Advocacy to influence policy

The principle

Appropriate advocacy and lobbying needs to be carried out at local and global policy levels so that the legitimacy of the intervention programme is widely accepted.

What the Sonagachi Project did

The project carried out extensive and on-going advocacy campaigns and individual lobbying with policy makers and opinion builders at all levels to persuade them of the legitimacy of their approach and to convince them that sex workers are entitled to equal rights concerning health and life. They targeted local opinion makers, local (elected) representatives of people, ministers, political party officials, human rights and other democratic fronts, women’s groups, trade unions, bureaucrats, intellectuals, other NGOs, and bilateral and multilateral donor agencies, international HIV-related networks and others. Consequently, the Sonagachi Project gained public recognition and wide acceptance, which in turn gave them the necessary manoeuvring room to carry out the more radical options. This gave them enough credibility as a programme to question and challenge some of the fundamental structural constraints that keep sex workers excluded from policy considerations and social participation, thereby rendering them more vulnerable to physical and social ill-being.
Empowerment and Linkages with other organisations

From its powerful start as discussed above, the Project went one step further. From involving sex workers, the Project is now managed by sex workers. Priscilla Alexander from the North American Task Force on Prostitution described the Project as “a rather traditional HIV/STD prevention project/clinic until Smarajit Jana, MD met representatives from sex work projects all over the world at one of the International AIDS Conferences. After the conference, he went back and emphasized community organizing as a model.” This lead to the project being run by sex workers.

In 1997, the women of the Project organised the Durbar Mahila Samawaya Committee (DMSC), Asia’s first union of sex workers and took control of the local government AIDS project. With 60,000 male and female members in West Bengal, the union worked for the decriminalisation of prostitution, for equal worker’s rights, and entitlement to negotiate working conditions. Union representatives who might never have dreamed of stepping outside the brothels, have flown as far as Geneva and Australia to publicize their cause.

Today, 430 peer educators spread awareness throughout Bengal, and 36 brothel-based medical clinics regularly treat sex workers. Among other things, DMSC has established a school for sex workers’ children, a money-lending co-op, and a cultural group that spreads AIDS awareness through music, dance, and street theatre. Sonagachi also organises an annual festival. Variations on the Sonagachi project model have been implemented in many other countries.

On the local level, their work has also inspired others, such as the City Counselling Center in downtown Kolkata which provides medical and psychological consultations, as well as cheap antiretroviral drugs and started one of India’s first PLWHAs support networks, the Kolkata Network of HIV Positive People.

Sources:

Conclusions: Sex Worker Case Study

This success story on sex work and HIV/AIDS offers lessons and inspiration. It repeats elements of the conclusions from the IDU case studies: peer education, building self-esteem through activities and the need to establish trust between communities through involving them as full partners as well as by other means. Although the range of activities of the project is vast, the simple answer given for their success is “responding to needs.”
This case study is not only about the involvement of affected communities but how affected communities can be involved in advocacy and policy-making. They targeted decision-makers, whether in government or media, trade unions, NGOs and more. They worked with pimps and clients. They advocated on both specific issues (i.e. police harassment) and also promoted a broad platform of sex worker’s rights.

The entire program was also based on providing skills and training to those who needed it. Starting from training to be peer educators, women moved into roles as project workers, then project managers. They represented themselves at regional and international conferences, and become union organisers and representatives.

The project put into practice the ideas emphasized in Chapter 2. They sought to create a non-judgemental enabling environment that supported their work, and examined factors which were not contributing to an enabling environment: social attitudes, legislation, police harassment. Then they carried out a broad-based advocacy campaign to work with stakeholders to achieve social change. A high mark of their achievements was to transfer control of the organisation from the government to sex workers themselves.

Another key concept is that the project originally began as a research exercise. Some of its success must surely have been due to their knowing the needs of the communities, the social and political context in which they operate, the key issues at the time, and opportunities for advocacy. Mapping this out, as they did, could be an important first step to understand how to involve affected communities, and further, how to do advocacy and policy-making.

Making linkages with other organisations was also important to their success. Going beyond its beginnings as a project to promote health, links were made with labour unions, sex work organisations around the world, local and national stakeholders, and the government.

It is worthwhile to note that there have been few sex work organisations in the world that have been able to replicate the success of the Sonagachi Project. Further exploration should be done on what factors have allowed them to achieve what has not been achieved elsewhere in the world.

**Gay Men / MSM Case Studies**

In many Western countries, gay men were the hardest hit by HIV/AIDS and the history of AIDS in these countries has been formed and shaped by gay men. The existence of established gay communities and community structures lead to a strong response to AIDS in many Western countries such as Australia and the United Kingdom. In many countries, HIV/AIDS changed the nature and politics of gay communities and activism.

Discussions of sexual identity in Asian countries have been complex. Men who have sex with men may choose to identify with a Western gay identity. At the same time, there are indigenous MSM identities in different countries. There is also the desire for men to create their own identities and movements that have independence from Western ideas and histories, for example, the tongzhi movement that is referred to below.
Organisations that work with MSMs in Asia must contend not only with these issues, but with a more universal context were same-sex sexuality is, at the least, ignored or devalued, and at the worst, leads to discrimination, abuse, violence and death. This makes HIV/AIDS work extremely difficult. In many countries, the level of MSM transmission of HIV/AIDS is unknown because same-sex activity is pretended not to exist. The following example, however, shows an organisation that is carrying out a wide range of activities in these areas with success and determination.

**Chi Heng Foundation**

**Summary:** This case-study describes the activities of the Chi Heng Foundation with a focus on where they have involved affected communities to carry out their work.

Chi Heng Foundation is a Hong Kong-based NGO which promotes the rights of sexual minorities and is also involved in HIV/AIDS awareness and prevention. In Hong Kong, Chi Heng has been involved in promoting the rights of the tongzhi communities as well as raising awareness and encouraging acceptance of the tongzhi community through public education and political advocacy. Chi Heng Foundation is able to do this effectively because it has involved an affected community - its staff and board members are made up of tongzhi and whose experiences inform their work. For example, public talks and seminars about tongzhi and HIV/AIDS issues in educational and healthcare institutions are generally done by tongzhi. Volunteers and officers of Chi Heng also regularly give talks about sexual orientation at local secondary schools and universities as openly lesbian and gay persons.

Chi Heng also follows this principle in promoting peer education through its outreach work. Many of the part-time outreach workers hired to regularly distribute condoms and educational material in bars, discos, saunas and male brothels in Beijing and Shenzhen are tongzhi themselves, and were already regular patrons of these venues before working for Chi Heng. They therefore have access to various informal networks, and can also perform their outreach duties without encountering too much resistance, whether it is with tongzhi establishments, or with male sex workers. While most male sex workers are heterosexual and are in the business for monetary rewards, tongzhi outreach workers will gain confidence and trust by being able to provide information on safer sex based on both personal and professional experience.

Another key initiative of the Foundation is focusing on the use of the Internet in the tongzhi community. Tongzhi staff members of Chi Heng were able to recognize the importance of this medium through their own personal use. Chi Heng co-organised and co-sponsored the first AIDS Conference for Tongzhi Websites in November 2001 in Beijing, just after the first National HIV/AIDS and STI conference was held there. The conference was attended by about 40 people from different parts of China who fund and maintain tongzhi websites. Perhaps the biggest benefit of the conference was that a national network of tongzhi websites was formed.

Using its expertise in HIV/AIDS, the Foundation promoted the use of websites for HIV/AIDS awareness. The conference included presentations by experts on the prevention of HIV/AIDS and STI and the legal rights of gays and lesbians in China. Among the issues discussed by the participants were the importance of and difficulty in...
promoting HIV/AIDS awareness and prevention; the dearth of funding and volunteers; the need to build relationships with and tap the knowledge of HIV/AIDS experts and medical professionals; legal issues; and the benefits of forming alliances with other groups and organisations, such as lawyers, the media, lesbians and feminists.

In 2002, Chi Heng sponsored and organised the First Tongzhi Website Awards to recognise and reward outstanding Tongzhi websites in three areas: health promotion, community service, news/information. Over 100 nominations of Tongzhi websites were received. Recognition and cash awards were given out in a well attended, fun-filled Award Ceremony banquet in the summer of 2002 in Beijing. Leveraging on the good relationship with tongzhi websites, Chi Heng conducted an on-line survey of MSM sexual behaviour in 2002, with a sample size of 2,500.

Chi Heng is currently preparing to host another conference for Tongzhi websites’ owners towards the end of 2003. Other future plans for the organisation include training workshops and capacity building programmes for MSM, volunteers and former sex workers in Beijing and Shenzhen; continued production of safer sex materials specifically designed for MSM; outreach work to saunas and bathhouses for outreach and condom distribution.

Source:
Chung To, Chi Heng Foundation

Conclusions: Gay Men / MSM Case Studies

The Chi Heng Foundation focuses both on HIV/AIDS and on the empowerment of men who have sex with men. In both these areas of work, they have involved an affected community, MSM or tongzhi, and tapped into their personal experiences and expertise to use in their outreach and education work. This is the key lesson of this case-study, and it is similar to the case study on PLWHAs involvement. The work that they have done to promote affected communities could only be achieved by the involvement of those communities. It is also likely that they have built the capacity of their organisation and of the individuals from affected communities by being involved in the activities described.

Another success was in identifying the popularity of MSM internet sites and the opportunity to work through this medium for health promotion. They then found ways of engaging the people involved and achieved great success: first a conference, and then a network. They managed to link their areas of expertise so that the network of websites will address HIV/AIDS issues. Like the Sonagachi Project described in the sex worker case study, Chi Heng also recognized the importance of building alliances: making links with other groups and organisations while keeping a clear focus on their priorities.

Gay Men and Sex Workers

As shown in the previous case study, work with men who have sex with men and sex workers often coincides. It is important to recognize both the links and differences between the areas, and to place the issues into local contexts to understand it better.
Gay Men organising to fight HIV/AIDS in Nepal

Summary: This case-study describes the work of the Blue Diamond Society and is an example of different issues converging: organizing around sexual identities, the rights of sex workers, and AIDS prevention. As has happened in many resource-poor countries, spaces for discussions between men who have sex with men have opened up because of HIV/AIDS. And also like many organisations, the Blue Diamond Society survives on few funds and must contend with harassment from the police and the public.

Seated in the pleasant confines of the Blue Diamond Society here in the Nepali capital, Sunil Panta and his peers voice their frustrations and fears in a society that largely views Kathmandu’s gay community as invisible, freakish, or abnormal. They talk about human rights abuse - verbal and physical abuse - rape, torture, blackmail, family apathy and denial, and the individual fear of coming out of the closet.

When Sunil frequented cruising sites in and around Kathmandu to seek like-minded individuals to found a support society for homosexuals in 2000, he almost gave up. But today, the Blue Diamond Society, formed in 2001, provides psycho-social counselling, sexual health services for homosexuals and male sex workers in Nepal and is a drop-in centre as well. “When I tried to register Blue Diamond Society with the Social Welfare Council as a non-government organisation working for the health of homosexuals, I was advised against it as it may lead to legal and social complications,” recalls Sunil. In the end, he registered it as an NGO working for male sexual health.

Sunil and his colleagues visit sites like Ratna Park in the centre of Kathmandu, Nepal where men come to seek out sex, paid and unpaid. Many of the sex workers are very young, not necessarily homosexual, but selling sex to keep themselves and sometimes their families alive. As with all the men there, they are at the mercy of the police, thieves and blackmailers who try to attack, rob or cheat them, sometimes following them home, threatening them, asking for “gifts” of money or their watches, and sometimes beating them.

In mid 2001, there were nine outreach workers, working six days a week, regularly visiting a dozen sites in Kathmandu, and without the time or resources to cover others sites they know of both in the capital and elsewhere. They are trained in STI and HIV prevention and techniques of approaching strangers without appearing either threatening or soliciting.

The outreach workers work in pairs, partly for safety. The challenges are enormous and not limited to overcoming the fear and ignorance of the men they try to meet. Sometimes the outreach workers are also targeted by blackmailers or the police. And there is a general air of suspicion, particularly at a time when terrorist attacks from Maoist guerrillas are increasing.

Their work is free form. They talk to the men, distribute condoms, provide information about common problems facing the men, and invite them to a “safe house” where they can relax, meet others and get counselling if needed. Every Friday evening there is a social meeting and on Saturdays there are films featuring men who have sex with men. And for those who can’t visit, there is a telephone hotline.
Lately the outreach workers have been focusing on blackmailer and police harassment, collecting information and advising the men how to be careful and help each other, show unity if anything happens. If a blackmailer or policeman is seen causing a problem, everyone runs to help the man under threat. The tactic is beginning to work and the police and others are more likely to go for men who have not come in contact with Blue Diamond.

That change is proof for the outreach workers that they are on the right track, even though, as Sunil says "what we are doing is a piece of sand in the ocean." Their goal is to help form a community and through that community "ensure that everyone is aware of their right to practise safer sex". But they need more volunteers and more money to cover their expenses when the current grant runs out. They are appealing to new donors, but as yet have had no reply.

Why do Sunil and his colleagues do this work? Society plays a role in the growing spread of HIV/AIDS in Nepal. Commented Martin Foreman, who interviewed Sunil for an article about Blue Diamond: "When society rejects you, or forces you into situations that you do not like, such as marriage, you are often subject to psychological problems that heterosexual men, or gay men in more tolerant societies, do not have to face. These include low self-esteem and the pressures of living a double life - playing the dutiful married husband, father and son, when you would prefer to be sharing your life and intimacy with another man. There can be legal problems, when the police or blackmailers take an interest, fear of losing your job and the respect of your family and friends.

"Then there are the health risks. You probably don’t know much about sexually transmitted infections and HIV, but what you do know is almost certainly related to sex with your wife. The idea that you might have sex with another man is ridiculous, and no-one is going to tell you how to protect yourself that way. So maybe you pick up a disease and don’t know you have it, or maybe you have some discomfort and you’re too embarrassed to go to a doctor. In either case, your next partner is likely to pick it up and pass it on.”

27 year-old Kishore Pandey is a government employee, a happily married man who loves his wife and has two children. But Pandey, in his own words, is living a third kind of life. "What do I lack? Why shouldn’t I have married? Nobody in my family can tell that I am gay and I could not tell them. I didn’t even know myself. I came to know about it much later." But unlike the majority of gay men who visit the Blue Diamond Society’s counselling centre and drop-in clinic, he is aware of the dangers of unsafe sex and the vulnerability of gay men to HIV/AIDS. “Gays do test for HIV. We enjoy having sex and, we have to be extra careful that we don’t harm others. I don’t think I can stop having sex if I am HIV-positive but I’ll continue to practice safe sex,” he says.

From small beginnings and through uncertain times in need of both human and financial resources, the Blue Diamond Society is playing a powerful role in educating vulnerable communities of both gay men and sex workers.

Sources:
- “Blue Diamonds in Kathmandu” by Martin Foreman (www.martinforeman.com)
Conclusions: Gay Men and Sex Worker Case Study

This case study of the Blue Diamond Society has some similarities to the case study above on the Chi Heng Foundation. Their initial work with MSM and gay men led to being involved with both HIV and health issues as well as working with male sex workers who do not identify as gay men. As a lesson for HIV and AIDS work, it shows the need to have a flexible approach that allows taking on board new issues. In many resource-rich countries, agencies needed to change according to the changing profile of the epidemic, for example, moving from working primarily with gay men to include work with drug users and straight men and women from ethnic communities or low socio-economic circumstances.

Again we find an example of effective work through involving affected communities. Through their outreach work, Blue Diamond uses the experiences of the people involved. The workers know locations to reach the men because they use the locations themselves. They can talk and relate to the men because they have shared experiences.

Similar to the sex worker case study, we note that a social and legal environment hostile to MSM interferes and obstructs their work.

I would also like to introduce the example here of the power of the individual or a few individuals to drive a response. Many CBOs and NGOs and the social movements that they represent are lead by one or a few key individuals. This has dangers as well. What happens if these individuals “burn out” - become too tired from working too hard that they are unable to continue? Or become sick? Or start to do work of poor quality?

However, a great number of case studies feature inspirational stories of people, such as those involved with the Blue Diamond Society, who work against adversity to achieve success, serve their communities and contribute to a response to HIV/AIDS or the strengthening of their communities.

This publication does not have time to explore this issue further, but readers might want to consider questions such as: How do we support these key individuals? How do we pass on their skills and experiences to others? And how do we build on their work to create sustainable structures that do not rely on individuals?

Migration Case Studies

When considering mobility or migration in relation to HIV and AIDS, the focus should not be only on the migrant workers themselves but on the conditions in labour migration work that make them vulnerable to the disease. Migration is a cyclical process that involves different stages, i.e. pre-departure, post-arrival and reintegration, and in each of these stages, the migrant worker experiences situations that puts his or her life and health at risk. Even in the pre-departure stage, where the migrant worker is still in the home country, they are more vulnerable to and at risk of infection of HIV/AIDS or other sexual transmitted infections (STIs). Reasons include: a low knowledge of HIV/AIDS; knowledge that does not translate into behaviour change; low condom use; and a feeling of indebtedness developed during the recruitment process.
Once they are abroad, migrant workers are exposed to various situations. Some of the conditions in international labour migration that make them at risk of HIV/AIDS infection include: homesickness, loneliness and social isolation; absence of social norms and rules from their own country or society; hostile immigration policies; lack of access to health information and services; and, the vulnerability of women migrants to sexual abuse. Because of the complex nature of overseas labour employment and the convoluted processes that are involved in the migration process, the initiatives and efforts to address the situation of overseas migrant workers, especially their vulnerability to HIV/AIDS, require a combination of strategies, approaches and actions. In particular, it necessitates concerted action from various key players and stakeholders in the migration and health sector as well as involving migrant workers themselves in the process.

Two case studies from CARAM ASIA and ACHIEVE

Summary: CARAM Asia, a regional network of NGOs involved in migration and health, works through local partners such as ACHIEVE in the Philippines. The following two case studies, reporting on work with seafarer’s wives and migrants living with HIV/AIDS, show a strategic, thoughtful and multi-faceted approach to addressing the vulnerability of migrants to HIV infection.

In 1997, CARAM Asia or the Coordination for Action Research on AIDS and Mobility in Asia, a regional network of NGOs involved in migration and health, began Phase One of a multi-country partnership. This involved planning, implementation and evaluation of a three-year action research project on the HIV vulnerability of mobile populations, specifically focusing on overseas migrant workers.

Initially a cooperation between Tenaganita (Women’s Force), a Malaysian women’s NGO and the Faculty of Medicine of the Free University in Amsterdam, Netherlands, CARAM Asia broadened its scope to implement a participatory action research in five other countries. These included: Bangladesh, Cambodia, Philippines, Thailand and Vietnam. Today, CARAM Asia has expanded its reach to include Indonesia, India, Pakistan, Nepal, and Sri Lanka.

In the Philippines, CARAM Asia’s focal point is Action for Health Initiatives (ACHIEVE), Inc., an organisation engaged in the development and implementation of an action-research programme on mobility and health, specifically addressing sexual and reproductive health and HIV/AIDS vulnerability of migrant workers and their families. Using rights-based participatory approaches, ACHIEVE endeavours to directly involve communities in the planning, implementation and evaluation of such initiatives.

The bibingka principle

ACHIEVE adheres to the bibingka principle in its approach to development work. Bibingka is a native rice cake made of glutinous rice flour, eggs and sugar. The batter is poured into a banana leaf or baking tin and cooked in between two layers of hot coals. Thus, cooking happens both at the bottom and at the top. In a similar manner, ACHIEVE works from both “ends” - at the community level, with migrants and their families and at the institutional level, with the government, whether at the local or national level. Other stakeholders in the migration and health arena, such as migrant support institutions and health care providers are also brought into the process.
Case Study: Working with Seafarer's Wives

In 2001, ACHIEVE began the implementation of Phase One of a program entitled, “Facilitating Change in Women’s Lives: Education and Capacity Building for Female Spouses and Partners of Seafarers.” This program was implemented in three communities in Davao City, Antique Province and Metro Manila, in partnership with seafarer’s wives associations and local NGOs.

Initial consultation workshops, discussions and interviews with the female spouses or partners of seafarers revealed that they are vulnerable to STIs/HIV/AIDS. This vulnerability is multi-faceted including biological, sexual, economic, and cultural factors. Thus, the women stated a need for information on reproductive health issues, STIs/HIV/AIDS and sexuality. They also wanted more skills in assertive communication, safer sex practices, home management, financial management, leadership and training.

As a result of these initial community building activities, ACHIEVE subsequently developed a capacity development program, in close coordination with key leaders of the partner organisations. There were two major program components that emerged: personal empowerment and community/organisational development. Both components had elements of knowledge enhancement and skills building. At the personal level, there was a need to enhance knowledge on issues related to migration, gender, reproductive health and sexuality. There was a need to build skills on home management, parenting, assertive communication, identifying health problems, safer sex, etc. At the organisational level, there was a need to build skills on training, advocacy and leadership and at the same time, enhance knowledge on the intersections between migration, gender, sexuality and reproductive health and rights, both at the local, national and transnational perspective.

With its partner organisations, ACHIEVE conducted a series of education workshops, seminars and skills trainings in the communities to implement the program. Each activity was concluded with the formulation of individual and organisational action plans. These plans were monitored by ACHIEVE and by the community leaders on a periodic basis.

The feedback by the organisations on ACHIEVE’s initiatives was positive and encouraging. Most of the women felt empowered by the knowledge that they gained in the seminars and trainings. Thus, in the subsequent monitoring and evaluation sessions that were undertaken, they confirmed the usefulness and value of their involvement in the program due to some improved changes in their personal lives. Some began going to health clinics for regular check-ups, especially, pap smears. The others started speaking to their seafarer husbands about HIV/AIDS. Some women have also started using condoms and have in fact, volunteered to be condom-use advocates.

While community education processes were taking place, ACHIEVE simultaneously established links with local government agencies and other service providers mandated to respond to the needs of migrant workers and women in general. Some of these were local health clinics, NGOs, and training centres, who could provide support or assistance to the female spouses and partners. Most of these institutions and agencies had little knowledge about the issues faced by female spouses and thus, they admitted that they had not been able to render services for the women in the past. With this new information, they indicated they would factor in such concerns in their existing programs.
Following the completion of the first phase of the capacity development program in the different communities, five key leaders and trainers from each community participated in a trainer’s training. This training was meant to build and enhance their skills in “echoing” their learning to their fellow spouses and partners in the communities. The “echo” trainings or seminars mark the second phase of the program when the women take ownership of the initiatives and undertake them in their own communities. To date, the group in Antique has begun conducting echo seminars. The trained trainers organised the logistics, planned the program and developed the discussion guide. They also looked for funding for the activity. In the preparations, they updated ACHIEVE on the progress of their plan. The seminar was concluded with an evaluation session. They have also recently undergone a second training of trainers to review and deepen their understanding on the issues.

Aside from the completion of the trainings, the program produced “Taking Control”, a series of manuals and education materials. The first material is a life skills manual for the female spouses and partners. The other is a discussion guide, intended as a resource material for trainings, workshops or other education activities for female spouses and partners of migrants.

Case Study: Working with Migrants Living with HIV/AIDS

In 2000, ACHIEVE organised focus group discussions and in-depth interviews with migrant workers living with HIV/AIDS. From these sessions, a number of issues were raised that needed immediate responses. This included the processing of their social security claims and benefits from government agencies; provision of employment and livelihood opportunities; the need for counselling, capacity building, and access to treatment. One of the immediate actions that ACHIEVE undertook was to organise and facilitate a round table discussion with key government agencies, migrant support NGOs and HIV/AIDS groups. Initially, the migrant workers provided testimonies about their experiences, focusing on the vulnerabilities that they experienced while working abroad. They also spoke about the impact of HIV/AIDS on their physical, mental, and emotional well-being and those of their families. They highlighted the specific problems that they encountered in the processing of their claims, such as stigma and discrimination of frontline personnel and the lack of proper systems and policies addressing HIV/AIDS-related cases for returning migrant workers.

This initial meeting resulted in the setting up of a “special” system within the bureaucracy of these government agencies to facilitate the processing of their claims. It also meant establishing a referral network and identifying focal points within the agencies, who would be given the task of attending to the processing of claims of returning HIV+ migrant workers. The latter strategy was meant to protect the confidentiality and privacy of the migrant workers.

Following the immediate response of the agencies involved, ACHIEVE sought to deepen its understanding of other concerns and needs of returning migrant workers living with HIV/AIDS. In 2001, it began an action research to determine the impact of HIV/AIDS on Filipino migrant worker returnees living with HIV/AIDS. Initial data from the research gave evidence to multiple layers of impact on the migrant workers, ranging from psychological, physical, economic and social. At the macro level, their situation and conditions had implications on health and migration policies and programs, not only for returning migrant workers, but also for those who were about to
leave and those already at the job site. The research also showed the impact on the immediate family of the migrant worker, particularly on the spouse or partner.

This new information resulted in a multi-pronged planning for appropriate responses and interventions. A number of workshops were held to analyse the problems, study possible interventions, identify stakeholders and create information materials. These were undertaken with the active involvement of key contacts in the community of migrant workers living with HIV/AIDS, especially those who participated in the action research. The results of these workshops were presented in a number of Stakeholder’s Forums organised by ACHIEVE at the national and local (city/province-wide) level.

In these activities, ACHIEVE believed that the involvement of the latter as advocates was of paramount necessity and could not be compromised if it were to engage in interventions addressing policy and program changes. There was a conscious move to veer away from the usual personal testimonies to actually enable them to make presentations on the issues. Thus, ACHIEVE facilitated numerous discussions with and among the migrant worker advocates and involved them in capacity building activities.

Today, ACHIEVE has migrant workers, some of whom are HIV positive, working as fulltime staff in the organisation. They are involved in advocacy activities on migration and HIV/AIDS, not just in the local and national level, but also at the regional level. They also form part of the training team that endeavours to inform and educate communities and various stakeholders on migration and HIV/AIDS issues.

In the discussions that had taken place, it was evident that responses to concerns faced by returning migrant workers living with HIV/AIDS had to occur on two levels. One was at the level of responding to personal and individual needs of the migrant workers. The other had to do with structural reforms, both at the policy and at the program level. On this level, ACHIEVE works very closely with the Philippine Overseas Employment Administration (POEA). An added dimension involving regional or international interventions and responses was also important given the transnational character of labour migration. This is where CARAM Asia as a regional network of migrant support NGOs working on HIV/AIDS comes in.

ACHIEVE realizes its limitations in direct service provision and thus aims to undertake advocacy on this issue and facilitate linkages with the appropriate agencies. The needs related to treatment and counselling, as well as family support, are currently being addressed by other HIV/AIDS organisations working directly on care and support issues.

The biggest gap remains to be economic reintegration. As former migrant workers, their main source of income previously came from overseas work. While there are occasional referrals and linkages with government and NGOs working on reintegration issues, a more proactive and strategic program is still lacking.

Also, ACHIEVE sees concrete links between mandatory HIV Antibody testing and the negative economic impact of HIV/AIDS on migrant workers. Those who are found positive are not permitted to work abroad, even if they are relatively healthy and free from other diseases and infections. Thus, ACHIEVE is currently involved in the
regional campaign of CARAM Asia against mandatory HIV Antibody testing of migrant workers. As part of its national initiatives to raise awareness on the issues among migrant workers, it conducted discussions with migrant workers on the issue. It also organised a Stakeholder’s forum involving representatives from government, medical clinics and laboratories, human rights bodies, migrant support NGOs, HIV/AIDS groups and migrant workers living with HIV/AIDS. The forum has resulted in the drafting of a strategic plan to address the issue, beginning with education among migrant workers, dialogue with medical clinics and laboratories, and advocacy and lobbying at the regional and international level. ACHIEVE does not foresee immediate victories, nevertheless, it aims to start making progress.

Other initiatives, such as community-based HIV/AIDS education for prospective migrant workers, have recently been started. ACHIEVE is also currently working with UNAIDS and the Philippine National AIDS Council to provide education on migration and HIV/AIDS issues to foreign-service personnel who will be stationed in Philippine embassies and consular offices abroad. These initiatives are meant to facilitate a broader understanding of the realities that migrant workers face at community and institutional levels. These initiatives are meant to facilitate a broader understanding of the realities that migrant workers face with agencies and institutions that are specifically mandated to render services for overseas Filipinos, particularly, migrant workers.

Source: Malu S. Marin, ACHIEVE

Conclusions: Migration Case Studies

The case studies on migrants and HIV/AIDS offer examples of both how to do effective advocacy as well as how to involve affected communities. CARAM Asia and ACHIEVE represent a slightly different model than some of the other case studies because instead of an affected community representing themselves, such as in the Sonagachi project for sex workers, ACHIEVE represented the interests of a vulnerable group, in this case, a group which would have difficulties forming an organisation. These case studies are therefore important for the methods that they describe in getting a direct perspective from these communities and incorporating it into their work. The numerous workshops, consultations and roundtable discussions not only involved migrants and their families, but they lead to concrete actions.

The working model of ACHIEVE is also one of collaboration. So, not only do they work with migrant communities, but they work with decision-makers in government. By acting as a facilitator between the two groups, they not only take into consideration the lived experiences of migrants into their work, but they encourage others to do so as well. They also show a clear understanding of their role and limitations and therefore, actively seek to work with others who can do work that is necessary but outside or beyond ACHIEVE’s remit or capacity.

It is also useful that the case studies describe the steps leading up to advocacy. They used research, consultations and discussion groups to develop understandings of key issues. They looked at what they had learned and developed strategic plans on what to do with it - Who should be involved? What needs to be achieved? How do we do it? They also recognized their own limitations, for example, in seeking collaboration with other organisations who are better at direct service provision.
A final key lesson from these case studies is the building of capacity of communities to do advocacy and education themselves. In the case of the migrant workers living with HIV/AIDS, ACHIEVE encouraged community leaders to take part in discussions, and then to speak, and then to advocate. With seafarer’s wives, training courses encourage them to bring their learning to a broader constituency while at the same time, embodying the principle of empowering those who are affected by an issue to be active and involved, find solutions, and spread the word.

**Human Rights and Anti-Discrimination**

**APCASO’s HIV/AIDS and Human Rights Project in Cambodia**

Summary: This case study is of a short project that was designed and implemented in response to the identified need of protecting and promoting the human rights of PLWHAs in Cambodia. The project used the strengths of the project implementer - APCASO’s expertise in building linkages between community-based organisations - towards fulfilling its goals.

The Asia Pacific Council of AIDS Service Organisations (APCASO) in partnership with FHI/IMPACT, UNAIDS and NGOs working on HIV/AIDS and human rights in Cambodia initiated an HIV/AIDS and Human Rights Project (the Project) in Cambodia in 2001. The Project grew out of a consultation on HIV/AIDS and human rights held in Cambodia in January and February 2000 which revealed that HIV/AIDS related stigma and discrimination were widespread and increasing as more people were diagnosed with HIV/AIDS. Although organisations were responding to the situation, there was a strong desire to increase organisational capacity and ability in this area.

The primary goal of the Project was to support Cambodian NGOs working in HIV/AIDS and in the area of human rights to address in practical ways the human dimensions of the HIV/AIDS epidemic in Cambodia.

The Project achieved the following outputs during its project period. A module on HIV/AIDS and human rights was developed prior to a training workshop, which was held in Phnom Penh over eight days in May/June 2001. Following the workshop, the Cambodian HIV/AIDS and Human Rights Network (CHRAN) was founded with the formalization of the Local Project Advisory group (LPAG) as focal point for network activities. An action plan focusing on three priority sectors - Family and Community, Employment and Workplace and the Health Sector was developed at the training workshop. Regular meetings were held with the LPAG and the three theme groups to discuss and further develop the action plan. In July 2001, a project evaluation meeting was held followed by a presentation of the Project to HIV/AIDS stakeholders. The network also carried out a field assessment in Phnom Penh and six provinces in Cambodia where over 400 people were interviewed to assess attitudes across a range of sectors towards people with HIV/AIDS. 200 people with HIV/AIDS were interviewed as well to develop baseline information on experiences of discrimination. In addition, the Network developed a structure and mechanism for dealing with complaints about HIV/AIDS discrimination.

What was unique about the project was the integration of human rights into existing activities, and that resources for activities were provided by network members. APCASO provided support to the network in the
form of co-ordination through the Local Project Co-ordinator, and technical support. Initial network activities and methods demonstrated that the project was “adding value” to the existing activities of the network members and was generating understanding and knowledge which were used to enhance programmes and activities.

The project enhanced and added value to the broader Cambodian response to HIV/AIDS in the following areas:

**A New Resource for the Cambodian Response to HIV/AIDS**

The Network provided a structure and forum for discussion and action on human rights and HIV/AIDS. In the future, expertise and experience in the area of human rights and AIDS could be developed by the link through project partners and regionally through APCASO. In a limited timeframe, the Network linked human rights and HIV/AIDS NGOs, two vitally important sectors in HIV/AIDS.

**Enhancing and Supporting the National Response**

The Network is now in a better position to become an established resource for stakeholders to support the Cambodian national strategy for HIV/AIDS, one which endorses human rights and the empowerment of local NGOs and communities to respond to the epidemic.

**Responding to a Shifting Epidemic**

There is an increase in the number of people with HIV/AIDS in Cambodia. This will result in a rise in the incidence of discrimination and stigma. As such, there is a need for a more intensive response from all organisations who will be able to draw on the Network’s support through its structures and mechanism for responding to complaints of HIV/AIDS related discrimination.

**Supporting People with HIV/AIDS**

The project can help the Network link with other PLWHAs organisations and groups to develop ways to assist their response to discrimination and to provide support in raising awareness about human rights.

Following this project, the Network has managed to raise funds in 2003 for several activities. Funds have been raised to establish an office and to engage full-time staff. Furthermore, technical capacity of the Network will be enhanced through the development of a human rights and HIV/AIDS curriculum based on the earlier module. The Network will build on its HIV/AIDS discrimination complaints mechanism by establishing a formal documentation system that will collect relevant baseline and monitoring data for their advocacy work which includes organizing public forums and producing UNGASS “shadow” country report. APCASO will continue to provide technical assistance to the Network.

Source: Asia Pacific Council of AIDS Service Organisations (APCASO)
Conclusions: Human Rights Case Study

This case study addresses the important issue of human rights and HIV/AIDS. Work in Cambodia started with surveys carried out by NGOs and CBOs to look at the lived-experiences of PLWHAs and the discrimination that they face. These resulted in actions and concrete outputs that used the experiences of affected communities and demonstrated different ways that organisations responded to the need to promote and protect the human rights of PLWHAs. These outputs included a new complaints structure and mechanism, a training workshop, and an action plan.

Of particular note were efforts to build the capacity of organisations to deal with the issue. This involved a number of steps including: introducing organisations to the issue, doing training workshops, and then actively involving them in work and projects. Most of the case-studies in this chapter describe the work of one organisation, but this case study goes further to describe the formal establishment of a network with appropriate bodies to support that network - an advisory group, staff, and an office.

Policy-making and advocacy often rely on shared resources and human capital between organisations and individuals that is not possible in isolation from each other. The oft-spoke of “multi-sectoral” approach can refer specifically to a different parts of government working together. But it can also apply to the community sector where it is necessary for NGOs, CBOs and PLWHAs groups to make links with other appropriate groups: faith-based organisations, labour unions, women’s organisations, business networks. With this example, we see appropriate organisations coming together to work with common and specific aims.

The work achieved above would not have been possible without resources, and this is a key question for improving advocacy and policy-making by NGOs and CBOs and involving them in a larger process. The organisations involved in this project had the financial means to develop it. Thus, we need to address not only the process of involving affected communities or developing their capacities but how we can obtain the resources to do so. How do we obtain or leverage funds from the appropriate multilateral agencies, donor agencies, resource-rich NGOs and CBOs, governments and aid programs?

Finally, in looking at the structural achievements of this case study, we should not ignore the content. As stated above in a number of case studies, a hostile social and legal environment interferes with the response to HIV and AIDS. This could mean active discrimination and human rights abuses directed at sex workers, migrants, gay men, MSMs, PLWHAs and IDUs. It could also mean a more passive discrimination such as a lack of legal protections and anti-discrimination frameworks for the above-groups. All types of discrimination obstruct the involvement of affected communities in a response to HIV and AIDS and interfere with the overall response. This case studies points out ways to addressing these problems.
Other case-study

As stated in Chapter One, many different communities of people are at risk and vulnerable to HIV infection. While this publication specifically aims at serving the constituencies represented by the Seven Sisters network, inspiration for case studies can come from many sources. In fact, they must come from many sources. No matter what communities we work or identify with, we can improve the way we work by looking outside of our own experiences to find lessons from other successful case studies.

Rural Farmers in Cambodia

Summary: Rural farming communities are at risk of HIV infection in Cambodia. An innovative program was initiated through the UNDP South East Asia HIV and Development Project (UNDP-SEAHIV) working with the Food and Agriculture Organisation of the United Nations (FAO) - Cambodia Integrated Pest Management programme (IPM) to empower farmers through Farmer’s Life Schools (FLS) to reduce vulnerability to HIV infection by reducing risk behaviours and encouraging independent problem-solving.

Cambodia was estimated at the end of 2002 to have 170,000 HIV positive people and an adult prevalence rate of 2.7%. Approximately 80% of the population are living and working in rural areas. While the most vulnerable groups in Cambodia are sex workers and drug users, if the Cambodian epidemic follows the path of Thailand or many African countries, the general population is vulnerable as well.

The Farmer’s Life School (FLS) project is an example of finding a model that works in another situation and adapting it for HIV prevention. The UNDP-SEAHIV and FAO IPM found in the Farmer Field Schools (FFS) an example of a participatory and community based strategy. The FFS aimed at maintaining a sustainable and healthy agricultural system. Using an analytical model called Agro-Ecosystem Analysis (AESA), it provided a forum for farmers to meet, work together and undertake field experiments with the aim of protecting their fields from pests, minimizing the use of pesticides, improving their yields and achieving sustainable income. By reflecting on their daily activities, they assessed which methods best benefited themselves and their community. Their work with other farmers encouraged their capacity-building by gaining new experience and expertise in:

- Technical issues concerning agriculture
- Leadership ability
- Self-confidence
- Working with groups
- Self-reflection and problem-solving

This model was adopted in July 2000 to establish the Farmer’s Life School. Rather than managing crops, farmers were asked to manage their personal lives within their communities. Each FLS is a simple school organised and led by farmers with eighteen to twenty farmers participating. On average, half were women. They met over a period of sixteen weeks to discuss issues with each other and farmers in neighbouring villages. The participants examine real life situations, real problems and real conditions from their villages and communities including risk
behaviours of farmers and factors that increase HIV vulnerability for individuals and communities. According to a presentation on the FLS:

The farmers...are the ones who control the process and the outcomes that, in their eyes, give it credibility. It is not a development activity imposed by a central government or a foreign donor agency. It is, in the true sense of the word, a grassroots approach. The farmers understand that by addressing the root causes of their vulnerability to HIV/AIDS, such as poverty or poor farm management, they can reduce vulnerabilities. When farmers acquire the capacity to build their future, preventing HIV infection by protecting themselves and their families becomes fully meaningful.35

Impact and Lessons:

As of December 2001, 24 FLS had been established in four provinces in Cambodia. There are 36 Farmer Trainers, 16 of which are women, who run these schools. They have trained 490 farmers, working towards mobilizing and empowering farmers to reduce their vulnerability to HIV/AIDS and other threats.

The farmers have developed leadership, networking, training, planning and organisational skills in their communities and strengthened farmers’ capabilities to make appropriate decisions and find better solutions to problems on their own without being reliant on resources outside their control.36

As a concrete example, farmers identified poverty as a cause of seasonal migration which could lead to loneliness and the risk of sexually transmitted infections and HIV. They became aware that income-generating activities during the dry season, such as cash crops or handicrafts, could be an effective HIV prevention strategy.

It is hoped that this example will be adopted for other rural programs in Asia, as well as encourage South-South cooperation.

More information on this case-study can be found at:

Mobile Populations and HIV Vulnerability: Selected Responses in South East Asia: [http://www.hiv-development.org/publications/Responses.htm](http://www.hiv-development.org/publications/Responses.htm)

Communities Facing the HIV/AIDS Challenge: From Crisis to Opportunity From Community Vulnerability to Community Resilience: [http://www.hiv-development.org/publications/Crisis.htm](http://www.hiv-development.org/publications/Crisis.htm)

Conclusions: Other Case Study

This case study on HIV prevention with rural farmers has been included in this publication as an example of a success story with a community that is vulnerable to HIV infection but not particularly marginalized.

36 “Mobile Populations and HIV Vulnerability: Selected Responses in South East Asia," UNDP-SEAHIV, March 2002
Some of the key lessons from this case study are:

- Adapting the strengths of existing programs for use in HIV prevention
- Using existing infrastructures and resources
- The success of participatory and community based strategies

All of these lessons can be applied or used for HIV responses involving marginalized communities. The lessons that we learn in our own organisations will be useful to others and we can learn lessons from those who we may not work with on a regular basis.

**Overall Case-Study Conclusions:**

This chapter described an approach to using case studies, and then presented a variety of case studies, most of which addressed the communities that the Seven Sisters network represents - MSM, Sex Workers, Migrants, and IDUs. They were drawn from a variety of sources including newspaper and internet articles, newsletters and case studies written directly for this publication. Because of the diversity of sources, the case studies speak with different voices. Some case stories are narrative, journalistic accounts, others are adapted from internet postings. They may describe only one aspect of the work of an organisation, or they may present a more comprehensive list of the activities an organisation is involved in.

Different case studies will offer different lessons, inspiration, and models for your work. On the other hand, you might find a case study where an organisation or situation is so different from your own that you will either not be able to use their example or you will have to think and act significantly different in your own cultural and political context. You may find the best examples from organisations that are doing similar work. Or you may find what you need by looking outside of your regular milieu.

Furthermore, each case study raises questions about itself and about the other case studies. They are incomplete because they are part of a larger story. I hope that the diversity of case studies and their different styles and voices can point out that we can learn similar and different lessons from each one. A small story about teaching young drug users to make videos may be as useful as a list of the structures developed to address human rights issues in Cambodia, depending on your organisation's context and how you apply lessons learned.

**Learning what not to do**

While the case studies here describe positive situations, you can also find examples of what you should not do. An omission from this publication is a section on negative case studies: examples of problems that organisations or activists have faced, and not overcome. What we are not succeeding at can teach us important lessons. However, it would be a mighty task to gather these stories. When organisations are fragile, and looking for funding and support, it is not a good idea for them to discuss or display for their failures to the public. Perhaps one day we can work towards being able to speak publicly and critically about our failures.
Some organisations have not been able to effectively advocate on behalf of their communities, or become involved in policy and advocacy-making for any of the following reasons:

- Lack of experience, expertise and leadership
- Incompetence of either leaders or workers in the organisation
- Competition between organisations doing similar work which reduced the effectiveness of both
- Financial mismanagement or scandal
- Moving too quickly - beyond one’s means or abilities
- Not having enough imagination or determination and moving too slowly
- Not building effective coalitions and partnerships
- Taking an approach that is too activist, or too passive for the situation
- Being unclear about goals and objectives
- Low morale of people involved
- Lack of reporting and accountability
- Inability to adapt to changing circumstances and maintain an organisation’s relevance
- Loss of skilled staff
- Lack of support from funders or government
- The particular set of circumstances are too difficult to overcome in this instance

Factors involved in unsuccessful case studies would range from problems with individuals, groups, the organisation itself, other organisations, funders, and the government or other external structures. The need for more expertise, resources, funds, and capacity may be a factor, as well as harder-to-measure issues such as good judgment, timing, the appropriateness of an approach, flexibility and adaptability. Sometimes the difference between success and failure is the simple belief that solutions will come from inside rather than outside an organisation.

**Learning what to do**

In the meantime, there are many related conclusions from the positive case studies in this chapter. Your organisation may be made up of people from affected communities, may represent affected communities, or may be looking for ways for their greater involvement. This summary of some of the key issues related to the case studies will offer different lessons to different types of organisations.

**Identifying Needs**

- In responding to HIV/AIDS and working with affected communities, organisations in these case studies looked at their local community to identify what was needed. Sometimes these needs will be plain and clear. At other times, they may need research, surveys or other methods to gather information. At all times, the people who will be affected by programs should be consulted with. Groups like ACHIEVE used consultation workshops, discussions and interviews to identify needs.
Ways of Thinking

- Responses to HIV/AIDS need to be flexible. Sometimes programs will be focused on only one or two ideas; other times they will be broad-ranging. Solutions to problems might come from looking to other organisations, or outside of the world of HIV/AIDS for solutions.
- Organisations may be able to adapt existing programs to new needs, or may need to create entirely new programs.
- Establishing clear goals and principles may enable effective work with affected communities, for example, the Sonagachi Project’s Respect, Reliance and Recognition approach.

Building the capacity of affected communities

- While your aim might be specifically in terms of HIV/AIDS prevention and care, affected communities may have other or additional priorities. Seafarer’s wives wanted training in home-management. Sex workers wanted literacy training. Listening and responding to the needs that communities identify is crucial.
- People gain skills step-by-step. Getting information can be a first step. Self-esteem through employment or participation in a workshop might lead to more active involvement in programmes. Aim high! Organisations like Sonagachi have seen sex workers become leaders of huge organisations!
- Peer education models can be useful for sharing information and building skills. Individuals that are empowered can empower other individuals.
- Affected communities can usefully speak from their own experiences to contribute to an HIV/AIDS response. They can also be encouraged to move beyond personal testimony to presenting on behalf of their communities and being involved in program development.
- Individuals are parts of families, and communities. Working with one person may require working with the other people that are close that person.

A Supportive Environment

- In order for a response to HIV/AIDS to be effective, and for affected communities to be able to be empowered, and then involved, there must be an environment that supports this.
- This shows the need for national legislative frameworks that promote and protect the human rights of affected communities, and may also include local ordinances, or agreements with important institutions such as the police or justice systems.
- The promotion of human rights and anti-discrimination, and community-based and participatory approaches create an environment more conducive to the involvement of affected communities.
Effective Partnerships and Coalitions

- Working with affected communities will require a spirit of partnership between affected and non-affected communities.
- Your organisation may not have skills or expertise in certain areas and may need to strategize on how to effectively collaborate with other organisations.
- Working with other supportive organisations can increase political power as well as facilitate programs on a practical level.
- Working with key decision-makers and powerful organisations will also be extremely important. Organisations in these case studies reached out to the government, industry, media, local authorities and others and worked hard to develop good relations.
- Many organisations working on the same issue could lead to the formation of a network.

The involvement of affected communities

- The knowledge, life-skills, and experiences of people from marginalized and vulnerable communities can be used to make programs more effective.
- Members of affected communities may know how to effectively communicate with and target their own communities.
- Peer education work is an effective way to reach affected communities - members of affected communities may be more comfortable interacting with others from similar circumstances and who have credibility in discussing or dealing with particular issues affecting the group.
- Our own organisations, as well as any body that is involved with the response to HIV/AIDS whether media, government, churches or networks, need to consider ways to involve affected communities.
- Programs may benefit from the involvement of affected communities, but may not be able to rely on them entirely. Many of the case studies used the model where individuals from marginalized and vulnerable communities worked with non-affected community workers.
- Members of affected communities may have particular needs or issues to be dealt with in order for them to be involved, i.e. drug users agreeing to avoid criminal activities while involved in outreach programs.
- Involving individuals in activities and projects is a way to build their capacity, leading to their ability to educate and advocate.
- Sometimes, key individuals will be important to the overall involvement of the community they represent and it will be necessary to find ways to support them and their work.
Questions for you

While these lessons may have implications for your work and that of your organisation, it will be necessary for you to ask yourself questions about how to apply them. Some issues you might want to consider include:

Context:

• What are the differences between my organisation and the ones described in the case studies?
• What are the differences in social and political context?

Inspiration and Planning:

• What activities in these case studies could realistically be undertaken by your organisation?
• What resources and planning are needed to do this?
• What organisations or key stakeholders would be useful to work with?
• How do we make links to them and when is it necessary to do this?

Building capacity:

• What practical skills do community organisations need to develop to function effectively?
• What resources and information are available for this?
• How can we build capacity and empower our organisation?

The principle of involving affected communities:

• How does our organisation work with affected and vulnerable communities?
• Can improving this also lead to improvements in our response to HIV and AIDS?
• What factors facilitate or inhibit the involvement of marginalized and vulnerable groups in our organisation?

Enabling environment:

• What factors facilitate or inhibit the involvement of our organisation in the overall response to HIV/AIDS?
• How can you create or lobby for an enabling environment to support your work? What legal or social frameworks obstruct your work?
Conclusion

This publication is written so that each chapter includes its own conclusions and a traditional conclusion that reviews each chapter and attempts to come up with an overall key message is unnecessary. The key message that we have sought to convey - that the involvement of affected communities in a response to HIV and AIDS is necessary to make that response effective - has been repeated and reiterated in many ways. We also hope we have provided information, ideas, and examples towards a key goal of the publication - for affected communities to be involved in global, national and local advocacy and policy-making.

Furthermore, we would like you to come up with your own conclusions from this publication. Aside from key messages which we hope everyone will have taken on, we hope that the questions raised and the information presented will lead you off in your own individual directions to think about what ways this book can apply to your work.

The word “conclusion” can also imply an ending - but this is not what we are hoping for. The global HIV/AIDS epidemic shows no signs of abating and our response to it must continue and grow stronger. This response will be an ongoing process that is built upon best practise, lessons learned and solid principles, such as community inclusion and empowerment. It would be “preaching to the converted”, or telling you what you already know, to speak again of how terrible the impact of this disease has been, and, even considering stories of success and enormous bravery and dignity, how inadequate the world’s response has been. So, we instead leave you with some encouragement.

Justice Edwin Cameron said:

By our action and resolutions and collective will, we can make the future different for many millions of people with AIDS and HIV for whom the present offers only illness and death.

Martin Luther King said:

It really boils down to this: that all life is interrelated. We are all caught in an inescapable network of mutuality, tied into a single garment of destiny. Whatever affects one directly, affects all indirectly.

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