



Why policy matters in the response to HIV

APMG

108/1 Erskineville Rd,
Newtown NSW 2042
Australia
Ph: +61 29519 1039
Fax: +61 29617 2039
ABN 21 106 054 326
www.aidsprojects.com

Table of contents

Introduction:	1
Responding to HIV – not as simple as it seems.....	2
The role of policy in responding to HIV	3
What is policy?.....	3
What does policy do?.....	3
What has been learned so far about developing and using policy in HIV?	9
Conclusion:.....	14
Case Studies	15
Case Study 1: Collaborative policy development in the private sector: Mexico.....	15
Case Study 2: The International Code of Good Practice for NGOs responding to HIV	20
Case study 3: National Policy - The Australian response to HIV ...	27
Case study 4: An organizational policy: The Salvation Army	32
Case study 5: A partnership between farm workers and land owners - Namibia	37

Acknowledgements: This discussion paper was written by Lou McCallum with assistance from Elizabeth Reid, Tim Leach and Felicity Young. Case studies were prepared by Kevin Ivers, Julia Cabassi, Meble Birengo, Lou McCallum and Deborah Bickel.

Please circulate freely, with appropriate acknowledgement.

Introduction:

After more than twenty years, HIV remains a difficult and complex problem, with infection numbers continuing to climb in many countries and access to treatment, care and support still impossible in many settings. There have been significant successes, but there are also many places where the response to HIV has not produced the results that many would have hoped for.

Responding to HIV occurs at many levels and involves individuals, families, communities and nations. There are many barriers to HIV prevention and care at each of these levels.

Policies and laws have been used to establish an environment that breaks down some of these barriers, providing support for decisions that individuals, families and communities make to protect themselves and others and to provide care. Setting up and maintaining this enabling environment has proven to be a difficult task in many places.

This paper focuses on the role that policy plays in making the response to HIV more effective. The word policy is used throughout the paper in its broadest sense, referring to the expression of what a group of people, an organization or a government thinks about something, or how they intend to act in relation to something or someone. This covers a wide spectrum, from formal expressions like a nation's laws to less formal expressions like a decision by a community to care for the families affected by HIV living within it.

The various roles that policy plays in the response to HIV and the lessons that have been learned in taking a policy-based approach are presented.

Five case studies are also included, to help illustrate the various ways in which policy operates in the response to HIV. These cover a range of settings and describe policies that operate at different levels: a development worker describes a process of policy co-operation between big businesses in Mexico; a grass-roots Salvation Army youth worker explains the role that her organization's informal HIV policy has played in grounding and shaping her work; people from a collection of international NGOs reflect on the impact that the process of developing an international code of conduct has had on their work; a national HIV NGO manager talks about the importance of a national policy that supports partnerships between sectors; and a workplace policy advocate describes the process of policy development between farm workers and land owners in Namibia.

Ultimately, the intention of this paper is to promote reflection and discussion about the tools that are being used to respond to HIV, and of the role that policy plays as one of those tools.

Responding to HIV – not as simple as it seems

At whatever level they operate – local, provincial, national, regional or global - HIV programs have three main goals:

- To minimise HIV transmission
- To improve the quality of life and life expectancy of people affected by HIV
- To minimise the impact of HIV on communities and nations

From the beginning of the epidemic these have looked relatively simple – you just secure the blood supply system, educate people to have safe sex and avoid needle sharing in injecting drug use, treat HIV positive mothers before childbirth and support, treat and care for people with HIV.

Achieving these goals has, however, proven very elusive. There been many disputes and disagreements about the best way to achieve these goals at all levels. There are many obstacles that get in the way and progress in all areas has been much slower than anyone could have anticipated.

In relation to the goal of reducing HIV transmission, some people say that this should be easy: 'You just inform people of the risk and they act in a rational and responsible manner – it is up to them', they say. But it is not nearly as simple as that. It is not just a matter of individuals acting rationally and responsibly. HIV prevention is trying to shape intimate and sometimes illegal behaviour. It is behaviour not just of an individual, but behaviour that occurs between people. It does not happen in isolation, but in socially constructed settings. It is one part of the complex and sometimes chaotic lives that people lead. There are issues of custom, knowledge, power, gender, need, poverty, emotion and culture that complicate this enormously.

Similarly for HIV care and support, the goal looks deceptively simple, yet it has been incredibly difficult to achieve. 'Make testing available, provide treatment, care for the sick', they say. But HIV presents significant challenges. Public health systems in many countries are already under extreme pressure and the arrival of yet another illness group, with expensive diagnostic and treatment needs comes at a time when the front-end of the systems – aid-posts and primary care clinics – have been significantly scaled back due to a lack of resources. Care is not simple either, when families, communities and health workers fear that they will contract HIV by providing care and when many people with HIV come from groups that are already on the margins of society.

The real complexity of meeting these HIV prevention and care goals presents many challenges. The development and implementation of policy has been one of the ways of responding to this complexity.

The role of policy in responding to HIV

What is policy?

There are many definitions of policy available. In its simplest form, policy is just an expression of what a group of people, an organization or a government thinks about something, or how they intend to act in relation to something or someone.

Our policy is to treat all people with HIV with dignity

Our policy is to offer free and voluntary HIV testing and counselling

Of course, policy can also be quite formal and binding, when expressed in law for instance. It can be complicated and cover a whole range of issues and situations. National HIV policies, for instance, usually set out how a country intends to approach all aspects of the national response to the epidemic, and can include statements about the general approach that will be taken, the priority concerns, the outcomes that are desired and the resources that will be made available.

Many people see policy as a piece of paper. This is not always the case. Policy, or the expression of how a group intends to act, might not be written down separately at all, or it might be embedded in speeches made by politicians, or in reports on important issues. Sometimes policies are discrete, referring to just one particular aspect of the HIV response, like access to treatment for prevention of HIV transmission from parent to child, or more general, like an anti-discrimination policy or law.

What does policy do?

Policy gives authority and provides legitimacy and permission

Many different areas of public policy impact on the national response to the HIV epidemic. Having a HIV policy in place provides the people working on the HIV response a level of authority to assist them in negotiating for what they need. A statement made by a government, a local jurisdiction or an organization about how they intend to respond to HIV gives the people within those structures the support they require to argue for changes in the systems they are working within.

Statements about HIV by leaders are extremely powerful. A visit by the Chinese Premier or by a British Princess to people with HIV in a hospital ward sends a message to the country that the silence is broken, that it is important to think about the country's response to HIV and that people with HIV are not to be feared or isolated. This, along with statements, speeches and more formal policy documents, gives community members, government officials, health workers and people in civil society organizations support to respond to HIV.

A statement of tolerance by a religious leader gives people permission to show concern and compassion and to challenge stigma, discrimination and rejection that might exist amongst the members of that religion or in the services provided by that religious group.

The Catholic Church in Papua New Guinea has a policy that HIV sero-discordant couples had the right to be informed about **condoms and their use**. This provides permission for church counsellors to be trained in HIV couple counselling and provides legitimacy for a discussion in this counselling about condom use. Without this legitimacy, counsellors were unsure where they stood in relation to condoms and lacked the skills to discuss these issues with parishioners and community members.

Public policies sometimes exist in tension with each other. A policy to reduce illicit drug use for instance may be at odds with a HIV policy that seeks to reduce HIV transmission amongst injecting drug users. Having an HIV policy in place gives people working on HIV some authority to approach and negotiate with people working in illicit drug control to ensure that outcomes are achieved in both areas.

Policy provides stability

HIV is a dynamic area of public health and development. It raises controversial issues that engender hot debate. It is bound up with sex, illicit drug use, morality, marginalization and death. These are highly emotive issues. HIV poses a significant threat to life and livelihood of individuals, families, communities and nations and as a result, people from all parts of society have views about how it should be responded to.

The personnel involved in overseeing the response to HIV, like health ministers, chief bureaucrats and local administrators, change regularly, and as each new person comes in to their post, there is a temptation to go back to the drawing board and change the direction of the response. This produces additional instability.

In the midst of all of this, policy offers an opportunity to dampen down some of this volatility and provide some stability. If key players in a nation, state, province or local jurisdiction can agree on the way that they will respond to aspects of HIV in the long-term, then changes in personnel will have less impact on the response.

In Indian states, for example, the multi-sectoral HIV response is led by a senior Indian Administrative Service bureaucrat, but a senior staff rotation policy means that these bureaucrats move regularly from department to department or area to area. In the absence of an agreed state HIV policy, this produces significant disruption, as the new administrator settles in to his or her new position. This also happens at district level in India, where District Collectors (the senior public servant in the district) are regularly moved from district to district.

The Governor of the Lao PDR province of Savannakhet has passed a **local law** that enshrines the province's approach to HIV and that buffers it from changes in local government that occur after local elections

Parliamentary Liaison Groups in some countries and states have had a stabilising effect. Broad agreement has been reached between political parties about the importance of a consistent HIV response, and subsequent changes in government have produced less instability than might have been the case if no broadly-agreed policy was in place.

In Malawi, the presence of a committed and active **Parliamentary Liaison Group** meant that the national HIV Strategic Framework could be developed in an environment of political stability.

In Australia, commitment to the National AIDS Strategy by all major political parties has meant that the broad approach to HIV has remained consistent for more than fifteen years and that controversial parts of the approach, like the existence of needle and syringe distribution programs for injecting drug users, have remained in place despite changes in governments at national and state level.

Policy provides consistency

An effective HIV response needs to be consistent across all settings, so that people are supported to maintain safe behaviours in all settings and people with HIV can access care and support wherever they are. Gaps in the consistent approach to HIV prevention and care increase people's vulnerability and can encourage stigma and discrimination, which drives people with HIV away from treatment care services.

Having policies in place can help to ensure that the approach to HIV is consistent across a range of settings. Here are some examples:

- Health system policies on HIV infection control help to ensure that all health workers provide safe and appropriate care, and prevent individual health workers or facilities from putting in place unnecessary measures that discriminate against people with HIV or people they feel might be more likely to be HIV positive
- Anti-discrimination laws and policies help to create an environment in which people with HIV and families affected by HIV can access the services and support they need
- Policies supporting voluntary HIV counselling and testing can protect people at risk from being tested without their consent, and can encourage health seeking behaviour amongst people from marginalized groups
- Policies can support the prevention work carried out amongst injecting drug users by ensuring that local police understand the role of needle exchange and peer education, and do not harass peer educators or users of these services

Policy shapes practice

One of the most important roles that policy has is the shaping of practice or behaviour. This is particularly important in HIV, where ignorance, fear and prejudice have resulted in high levels of stigma and discrimination against people affected by HIV. Policy can set out for employers, for health workers or for a community, how they are expected to behave. Good policy will also tell them why they are expected to behave that way and what positive and negative outcomes might result from their behaviour. People are more likely to comply with a policy if they have been provided with a chance to understand why it is there.

Policy can take the form of a positive statement from a group or organization about how they will treat people with HIV and people vulnerable to HIV. In this case, it acts as a standard-setting and accountability tool, encouraging clients of a service or members of an affected community to measure the performance of service providers against their stated policy.

The Papua New Guinea National AIDS Council Booklet on HIV testing sets out the country's **policy on HIV testing**.

The policy states that all people tested for HIV are to receive confidential counselling, information, follow-up support and referral. This can shape behaviour in the following ways:

- It tells the service planners or facility managers that they need to set the service up so that it can provide these essential elements
- It tells them what human resources will be needed and what skills they will need to have
- It tells the health workers what they will need to do for each client that comes for HIV testing
- It tells clients coming for the service what they can expect

<http://www.nacs.org.pg>

The Republic of South Africa **HIV and schools policy** ensures that children affected by HIV can attend school. This can shape behaviour in the following ways:

- It provides principals and teachers with guidance to ensure that they do not exclude or in other ways discriminate against children affected by HIV
- It encourages families affected by HIV to send their children to school
- It demonstrates to parents of other children at the school that the health and safety of their children has been taken into account
- It promotes community tolerance and acceptance of families affected by HIV

<http://www.education.gov.za/content/documents/447.pdf>

The Humsafar Trust, an NGO working amongst men who have sex with men in Mumbai, India, has an **Organizational Policy Manual** that sets out for staff, volunteers and its community, the organization's approach to its work and the policies that guide that work.

- It tells the individuals within the organization what is expected from them, setting out their rights and responsibilities
- It is a useful orientation tool for new staff, ensuring that service quality is consistent
- It provides clients of the service with an insight into what they can expect from the organization and from individuals within it
- It helps create a consistent organizational culture
- It assists managers to carry out performance feedback and disciplinary procedures if necessary

<http://www.humsafar.org>

Policy informs and teaches

Good policy can impart information and can teach people about the issues surrounding HIV. The policy development process can bring new players into the HIV response and can educate them about the approaches and strategies that work. It provides an opportunity for people to raise their concerns, debate the range of possible responses, gain access to information about approaches that work and agree on an approach that meets their needs.

Policies form an essential part of staff orientation and can be an effective tool for ensuring that changes in staff do not result in changes in the approach that a service or organization takes to HIV prevention and care.

The HIV policy for **UN Staff Members and their families** is a comprehensive document that educates UN staff about the basics of HIV and describes the UN system's approach to staff and family members affected by HIV.

Its strengths are:

- It starts with the basics, not assuming that staff already know about HIV disease transmission routes, safer behaviour and HIV management
- It contains clear, concise language and explicit diagrams about safe sex
- It makes the UN position clear and provides authoritative information to deal with myths and misconceptions
- It is therefore a very useful staff orientation document

<http://www.unaids.org>

Policy creates consensus

The process of HIV policy development has been a key catalyst in bringing people together to identify common ground. The partnerships between government, business and civil society that have developed as part of the response to HIV have been very innovative and have provided leadership for other areas of health and development. The involvement of people with HIV, though perhaps not fully developed in some places, has been a key element of this.

A policy document, at national, provincial or local level, can represent this partnership and demonstrate that there is broad agreement from all sectors. The policy development process, and the eventual implementation of the agreed policy, can bind partnerships together. It can demonstrate to affected communities and other interested parties that their concerns are being listened to and acted upon. In many places, it has brought about a shift from adversarial advocacy to a constructive negotiated partnership.

The development of an **International Code of Good Practice for NGOs** working in HIV was seen by some as a useful strategy to promote accountability and consistency. There were fears, however, that it would be impossible to identify common ground across such a diverse sector, particularly in areas of condom promotion and effective work with injecting drug users.

The Code development process itself provided a forum for the discussion of these issues and for the development of broad consensus on a range of issues. In this case, the process of policy development has been instrumental in identifying common ground and building consensus.

See case study 2

Policy provides a framework for collaboration and partnership

Obviously, the production of the policy is not an end in itself. Partnership in the response to HIV is a dynamic thing and needs to be continuously nurtured if it is to succeed. Not all policies are implemented. The existence of the policy does not always solve the problem, but often the policy development process acts as a starting point for on-going negotiation and collaboration.

Farm workers and land owners in Namibia have been assisted to work through a difficult process to negotiate HIV workplace policies that assist in creating family-friendly working conditions, access to a safer working environment and treatment, care and support services.

See case Study 5

Big business in Mexico has participated in the creation of a national business council that has guided the development of private sector policies to eradicate stigma and discrimination against people with HIV in their sector.

See case study 1

Policy breaks the silence

One of the most significant barriers to the response to HIV is silence. Many people living with HIV and families affected by HIV fear stigma, discrimination and rejection and withdraw from participating in community life. Communities and nations feel ashamed that they have HIV in their midst and fear that it will affect the way that they are perceived by the rest of the world. Some politicians do not want to be associated with an issue that is controversial and likely to embroil them in debate. Police services do not want any attention brought to the fact that illegal activities like sex work, male to male sex and illicit drug use are going on in their jurisdiction, fearing that they will be blamed for not providing their community with protection from these activities.

Policy provides an opportunity to break this silence and to have discussions in families, communities and nations about these issues in a constructive way.

The Asia Pacific Leadership Forum on HIV & AIDS has provided an opportunity for political and community leaders from across Asia and the Pacific to come together and speak openly about HIV in that region and globally. Leaders have been challenged by each other to spell out their commitment to the response to HIV and, in many cases these clear statements of commitment have broken the silence about HIV.

http://www.policyproject.com/pubs/generalreport/ANE_ActNow.pdf

What has been learned so far about developing and using policy in HIV?

HIV policy has been around in a variety of forms for some time now. There have been plenty of examples of good policy and not-so-good policy. Some of the lessons that can be drawn from the development and use of HIV policy include:

Policy development is a dynamic process

There have been many attempts to define the policy development process. Some describe it as a discrete linear process with a series of inputs that lead to a policy outcome¹. Others propose that policy development is circular and involves a continuous cycle of information-gathering, consultation, development, review and reform.² Porter

summarizes the range of theories about policy development and comes to the conclusion that 'policy making and policy learning occur within a web of interacting forces, involving multiple sources of information, complex power relations and changing institutional arrangements.'³

Kingdon identifies three streams (political, problem and policy) as the main ways in which people interact in the policy process.⁴ This is a tidy model, but in reality people rarely stay in one stream – experts operate in a political context, politicians choose their own experts, advocacy groups sit at the policy-development table whilst throwing stones at the building.

Most agree that there is a set of competing or collaborating forces at play in policy development and that paying attention to these is the key to success. All these theories attempt to describe what people in the HIV response have come to know as a dynamic and difficult area.

Some HIV policy development is neat and tidy. Problems are identified by PLHA, people at risk, lawyers, advocacy groups, communities, NGOs, public health officials and other players. These problems are passed on to decision-making structures – advisory committees, networks and government departments. Solutions are developed using knowledge generated by researchers, NGOs, epidemiologists and others. These solutions are put to decision-makers for adoption.

At other times the policy development process is much more haphazard. An issue arises in the media or as a result of advocacy. A range of potential responses are possible. People exert influence in a variety of ways to bring about the solution that they think is most appropriate. Both these extremes operate in most places.

In some places, the policy development process has been stabilized by putting in place a set of building blocks:

- **The establishment of a policy community** – encouragement for the participation of a range of sectors in the dialogue about approaches to HIV. This means that when new issues arise, they can be fed into an existing dialogue.
- **Policy accountability** – a clear set of arrangements that hold policy-makers accountable to the HIV sector and the community. This sustains the effort of people involved in the HIV response by showing them that their advice is being heard.
- **Structures and institutions for policy input** – providing entry points for participation. This shows people that no matter where they are in the response to HIV, there is a place to take their problems and clear pathways for participation in solution identification. These structures and institutions make the policy development process more transparent.
- **Arrangements for peaceful competition for policy power** – reducing nepotism and corruption and providing space for all people with knowledge and experience to participate in the policy development process.⁵

Knowledge-based policy works better

It seems obvious to say that if HIV policy is to succeed, it should be based on a clear understanding of the way in which the HIV epidemic presents itself in the place in which the policy is supposed to operate. Asking a simple question like 'Exactly what problem is this policy supposed to fix?' has been a crucial first step in the development of effective HIV policy in many places. Forgetting to ask this question has led to the adoption of policies that work against the broad goals of HIV prevention and care.

Policies that have been imported from other places with little effort to adapt them to local circumstances, or that have been developed quickly without a clear understanding of the context, have had less positive impact.

The identification of best practice has sometimes worked against local knowledge. One of the key mechanisms for policy transfer in HIV has involved the development and marketing by international organizations of a set of best practices.⁶ Knowledge and experience is developed in the field and models and approaches identified and documented. These are taken up by international organizations, packaged and then marketed to other countries facing similar problems. There have been several problems with this approach, identified as:

- Sometimes the things that are identified as essential elements are incorrect and crucial process steps are not included
- It misses out on the critical role that local actors play in social change
- The people developing and packaging the best practice may not have had first hand experience of the model they are packaging
- Donors sometimes insist on the implementation of a particular model, allowing little space for local adaptation
- Sometimes the local specialists who developed the model or policy are recruited into the international organization to promote their model, and their certainty about the success of their particular approach works against local adaptation and innovation.

Knowledge alone does not shape policy. Knowledge has to be offered in a way that can be understood and accepted by decision-makers. It has to be offered by people who decision-makers can trust and it has to be credible.

Knowledge and evidence contributes more to policy when:

- It fits within the political and institutional limits and pressures of policymakers, and has resonated with their assumptions, or significant pressure is exerted to challenge them;
- The evidence is credible and convincing, provides practical solutions to pressing policy problems, and is packaged to attract policymakers' interest
- Researchers and policymakers share common networks, trust each other, and communicate effectively.

ODI Briefing Paper⁷

A set of clear values provides a stable foundation and makes policy adaptable

Policies that simply state how a person, organization or country is to going to act in relation to a particular issue have had less impact than policies that provide a framework of values and guiding principles to assist people to deal with problems as they emerge. The HIV epidemic is dynamic and presents individuals, communities and nations with on-going challenges.

The Malawi National HIV Policy contains a set of guiding principles that act as a foundation for the country's on-going HIV response. As new issues arise, the clear intent set out in the guiding principles is the primary reference point for community members and decision-makers. All new policies or positions taken have to be consistent with these principles.

These principles cover:

- Political leadership and commitment
- The need for a multi-sectoral approach and the promotion of partnerships
- The need for a public health approach
- The promotion and protection of human rights
- The greater involvement of PLHA
- A commitment to good governance, transparency and accountability
- Support for scientific and evidence-based research

http://www.aidsmalawi.org.mw/resources_code/index.asp

Timing is everything

Some people seem to carry HIV policies around in their back pocket, just waiting for the right time to get them adopted. This often happens in times of crisis, when a government or community is facing an immediate problem and wants a quick solution that takes the problem away.

Kingdon coined the phrase 'a policy whose time has come' and this appears to be particularly relevant in HIV policy⁸. Governments that have been particularly resistant to a knowledge-based policy approach often become more receptive when they have an immediate problem to solve. The people who have been most successful at influencing policy development have been those who have understood when and how to push a particular approach and when to sit quietly.

Drawing on the 'streams of influence' model, windows of opportunity for policy change open when the three streams converge – a problem is identified, a viable solution is available and there is political will to endorse and implement it. It has proven easier to get these streams to converge when the people from each stream know about each other and have structures that allow them to interact and trust each other.

Some of the best advocacy groups have been those which have known when to push and when to sit quietly. There are many ways to influence policy. Sometimes it is as simple as laying the facts before the decision-makers, though this is more successful when the approach proposed is in line with what the society generally wants⁹.

Sometimes it can be done through negotiation and by enlisting the support of key people who can directly influence decision-makers. In some cases it takes direct confrontation. Choosing the right time for each approach is crucial.

Networks produce results

Networks have made a significant contribution to the development of international, national and local HIV policy. UNDP has supported the development of over thirty regional, national and local HIV legal, ethical and human rights networks and has drawn out a set of lessons learned from this experience.

'Networks can be a forum for bringing together key stakeholders including people living with HIV, ethicists, lawyers, health professionals, human rights and women's advocates, and others, to work towards building consensus on effective responses to the diverse challenges raised by the HIV epidemic. Potentially, networks are an important capacity-building mechanism. They can be uniquely flexible and sensitive to changing needs and situations, and strong in consensus-building and the implementation of sustainable solutions.'

UNDP Networks for Development¹⁰

Networks have also played a key role in advocacy for policy change. Individuals and organizations have formed networks as a way of protecting themselves from the risk of opposing government policy. Networks have also increased the legitimacy of their arguments by broadening the base of support. Support for PLHA networks has significantly increased the ability of PLHA to participate effectively in the policy development process.

Everything is connected

Policies do not have to be about HIV to have a direct impact on HIV. Changes in other areas of policy, for example in law and order or in social security entitlements, can have a direct impact on who gets HIV infected and who receives adequate care and support. The impact of policy changes spreads out like ripples in a pond, with the potential to have both positive and negative effects.

Free Primary School Education as a HIV prevention measure

The central message ... is that the education of children and youth merits the highest priority in a world afflicted by HIV. This is because a good basic education ranks among the most effective – and cost-effective – means of HIV prevention. It also merits priority because the very education system that supplies a nation's future is being gravely threatened by the epidemic, particularly in the areas of high or rising HIV prevalence. Thus countries face an urgent need to strengthen their education systems, which offer a window of hope unlike any other for escaping the grip of HIV. Vigorous pursuit of Education For All (EFA) goals is imperative, along with education aimed at HIV prevention.

Multi-sectoral approaches to HIV policy development have reduced the risk that policies from one sector will impact negatively on the outcomes being sought by another sector and have increased the possibility of improved HIV outcomes from changes in mainstream policy.

Conclusion:

Policy matters. It is not the only thing that matters in the response to HIV, but its absence leaves space for inaction, confusion and inconsistency. There are many choices to be made in responding to HIV. Some lead quickly to the achievement of outcomes that reduce HIV transmission and support individuals, families, communities and nations affected by HIV. Others soak up valuable resources with little impact. A dynamic policy environment helps to steer people towards the right choices.

Case Studies

Case Study 1: Collaborative policy development in the private sector: Mexico

Prepared by Kevin Ivers, Center Strategies, Washington

When the AIDS Responsibility Project (ARP) sponsored a Congressional delegation (CODEL) trip through Latin America to investigate the state of HIV, and current U.S. efforts to assist the region, we saw a wide range of needs and gaps. But one thing was clearly common. When we asked what the greatest problem was, we heard the same answer from government officials, medical professionals, journalists, activists and people with HIV – stigma and discrimination.

Indeed, it was the one major impediment to successful national HIV strategies that all of the countries were having a difficult time addressing. On our visit to Mexico, every HIV-positive person we spoke to had been fired at least once from a job because of their status. The need for policy work – and tangible policy outcomes – was very evident.

It was a familiar situation to the ARP team. We'd each begun our HIV policy work in the 1980's in the towns and cities of the United States, where stigma had been an enormous barrier to effective solutions and caused a deepening of the epidemic before the first major national legislation was passed in 1990. We knew the U.S. experience would inform our work in a vulnerable region like Latin America, where stigma was rampant and deep-seated, and little had been done – or even tried – in terms of policy development to address it.

We set out, with our partners in the POLICY Project, to create a national business council to bring the business community of Mexico to the table with the national government and the leading HIV NGOs. But for such an effort to result in tangible policy outcomes, the Mexico business council would have to be founded and driven by the companies most committed to such outcomes within their own walls. Otherwise, it would be a council on paper only, without much substance.

When talking of business leadership on HIV, many forces must be balanced in order to maximize the tangible, long-term results. The urge to see HIV as a matter of corporate social responsibility, or something relegated to the company's foundation, must be overcome if the goal is to produce tangible policy outcomes impacting a wide spectrum of workers. So, a company must see the value in policy development, which requires a serious commitment from top brass to happen. This was our first challenge.

We decided that the best way to initiate contact with our company targets would be to conduct a corporate survey on policies and practices. It would not only create a benchmark of information on where the Mexican workplace stood on the issue, but it

would also be the right context to begin our dialogue with the HR departments and the senior management of these companies.

Companies, especially large multinationals, typically do not come to the effort with good relations with HIV activist organizations, or government ministries for that matter. Often, those feelings are mutual, as confrontation among the three sides of the national strategy triad - government, private sector, civil society - has often been the rule on HIV and not the exception in many countries. Building trust is vital, and companies must be trusting of those coming to them in such an effort or they will not become meaningfully engaged.

The ARP team sought to build trust with the target companies from the outset. We decided early on that, as a U.S.-based NGO funded by U.S. government money, it would be more appropriate to target U.S. companies operating in Mexico at the beginning. Our team also had strong corporate contacts in the U.S., and we would usually walk into a first meeting in Mexico City having already been introduced to our counterparts by their higher-ups in New York or Detroit or elsewhere in the U.S. We found that once a call had been received from headquarters, they were much more eager to receive us and, more importantly, trust us.

Of all the countries in Latin America, Mexico was the best candidate to build a model program. Its close economic ties to the United States and the prominence of U.S. multinationals in the business community gave us a greater chance at success.

We also had vital political support, which was necessary to meet our ambitious objectives in a short time. The National AIDS Program of Mexico, directed by Dr. Jorge Saavedra, was an early and strong supporter, and collaborated on the design of the program. Secretary Julio Frenk of the Ministry of Health gave his personal support to the effort by appearing at public events and mentioning it in his speeches on HIV policy and in the government's new public campaign against homophobia and discrimination.

Also critical to us was the financial backing of the U.S. Agency for International Development, which fully funded the program, and the political and public support of U.S. Ambassador Antonio Garza, Jr., dubbed "the second most important man in Mexico after President Fox" by many we met with. Ambassador Garza spoke at every public event we held to promote our effort, and spoke publicly and privately with leaders in the business community to urge their participation early on, when few in Mexico knew who we were or what we intended to accomplish.

The corporate survey, released in September 2004 at a public press event, identified the strengths and weaknesses of policies and practices among 20 of the top U.S. employers in Mexico across a number of sectors. The companies ranged from Wal-Mart, the largest private employer in Mexico, to manufacturers like Ford, Pfizer and 3M, to service industry leaders like Banamex, FedEx and PriceWaterhouseCoopers. We identified leaders as well as gaps, but overall we learned that while nearly all these companies had HIV-specific policies in the United States or otherwise complied with U.S. federal laws on HIV in their home operations, few of them had such policies in Mexico beyond generic anti-discrimination language.

Immediately, ten of the surveyed companies came back to us and asked for help in developing HIV-specific policies. In many cases, their Mexican HR departments hadn't even been aware of the disparity with their parent companies. While the disparity was completely legal, it was still something that provoked advocates on the inside who wanted to address it. Political will on the inside had been generated by the survey.

Those ten companies were the founding members of the Consejo Nacional Empresarial sobre SIDA (CONAES), launched on December 1, 2004 – World AIDS Day. The mission statement of CONAES was simple – the member companies were committed to the eradication of HIV-related discrimination in their workplaces. It was a unifying mission, which we knew would have to be implemented by the companies themselves, taking action inside their walls and changing their policies.

However, if CONAES had any chance of growing beyond these 10 U.S. multinational companies, we would have to build a broader value for the effort beyond the leaders. We'd have to coax in the sceptics and the hold-outs and bring in the major Mexican companies, or it would lose momentum and credibility. It would also not amount to a broad impact among the wide segment of Mexican workers we intended to help.

Right away, we developed the “bottom-line argument” which we would introduce at the first meeting when recruiting for CONAES. It arose out of the survey. We informally asked all 20 surveyed companies how many HIV-positive employees they had every known to have in their ranks. Within a sample of 300,000 total employees among them, a total of less than 15 were reported to us by the HR departments we spoke with. Since we know that 3 in 1,000 Mexicans is HIV-positive, and factoring in that most are likely not in the formal economy, the total number of HIV-positive individuals at these 20 companies is at least in the hundreds.

Sharing this with the companies startled many of them. Not only did it mean that many of these employees were not accessing the medical benefits they were entitled to by concealing their status, it also meant these companies could not accurately assess risk within their workforces since they had no idea how many people in their companies had HIV. It was a clear indicator of the gap of trust between employees and management, despite the policies they currently had in place, and the pervasive impact of stigma on their companies.

Throughout 2005, ARP and the Futures Group worked with the CONAES members to identify their needs and develop tools to address them. The Futures Group had developed a software program called the Workplace Policy Builder, and translated it into Spanish, which could be used by corporations to build a customized HIV-specific workplace policy. The team also helped organize the leading Mexico NGOs into a network, called Impulso, and began a series of technical assistance training sessions to build the network's capacity in providing expert consulting services to the CONAES members directly as they developed policies and practices, as well as monitoring and evaluation systems to make them effective.

Over the course of the first year, we moved quickly to establish value for membership. No membership fee was charged, which kept the focus on policy outcomes. We solidified the companies' public will and support by conducting a national conference of CONAES in June 2005. The only requirement of membership we established at the outset was that every member company would have to make a public presentation at the conference detailing what they each were doing inside their companies to achieve the mission of CONAES. In due course, the companies all asked for our help in making their presentations, opening up more avenues to identify strengths as well as gaps which needed to be addressed. We decided to make the conference an annual event, which would put added pressure on the members to continuously produce new results to report each year.

We also aggressively recruited new members to CONAES, one company at a time. We continued reaching out to U.S. multinationals, which created positive pressure on Mexican companies to consider joining rather than be left out. More productively, though, was leveraging the supply chain method. Mexican companies were usually the primary suppliers to the leading companies in CONAES, and they told us that their management would be highly responsive to an effort that their leading customers wanted them to join.

By the end of 2005, we had 28 member companies, including a number of Mexican companies, and the four leading HIV NGOs were unified in a services network to partner with the companies on policy development. We'd also had several public events around CONAES, featuring speeches by leading Mexican and U.S. government figures in Mexico as well as leaders in the business community. Every member company had made public presentations on the tangible actions they were taking to fulfil their anti-discrimination mission. The Mexican media had extensively covered our work, and begun to study the issue of workplace discrimination on HIV with commendable depth.

We had prepared the ground, but the challenge of making CONAES something other than a PR success story was the greater hurdle to jump. We knew that the critical moment would come in the series of CONAES business meetings to follow the June 2005 national conference. In those closed rooms, away from the cameras and with the company representatives at the table, we would have to talk about raising the bar for results. We'd have to call on the companies not only to follow through on their own policy promises, but to bring in other companies and to invest financial resources in the long-term sustainability of CONAES as the core forum for this activity going forward.

We had to make it clear that we would be leaving the effort in a year, and it was incumbent on them to take what we'd all created together and make it their own in a way that guaranteed ongoing results.

By the time we reached this stage, there was a strong core of leaders from the companies in the room when CONAES had a meeting. They would form the interim executive committee of the council, and had become the advocates for moving forward with solid results and meaningful investment of money. As the companies who'd been involved from the beginning, they had come to recognize the value of the activity, and

had become articulate spokespersons inside the group. This was a major step forward for the sustainability of CONAES.

Our hard work at building trust and value was rewarded when CONAES voted to require that all members of the council adopt HIV-specific workplace policies in 2006. Furthermore, CONAES would invest US\$1,000 per company in 2006 in the Impulso NGO network, which would provide technical assistance back to the companies to achieve their policy goals. This was the turning point in the project.

By then, the project had already leveraged over \$150,000 worth of internal corporate resources and small-scale sponsorships related to the CONAES effort. Once the 2006 policy goals would be met, it would mean that over 130,000 Mexican workers would now be directly covered by HIV-specific workplace policies within companies that had made a substantial public and financial commitment to ensuring those policies were effective.

It also meant that a substantial core of the business community in Mexico was publicly leading the way in responding to HIV – not with mere token support, and not as a measure of their corporate citizenship. They were setting a new standard in terms of policy, and reinforcing the economic arguments in favor of reducing stigma and eliminating workplace discrimination related to HIV. They were investing resources in the leading organizations which provide front-line services not only to the companies themselves, but to a wide range of people with HIV in the informal economy as well.

It is upon this strong foundation that CONAES can transition from a project a small group of committed Americans and Mexicans launched in 2004 to being a policy leader and a catalyst for positive change in Mexican society. Our work will ultimately be judged upon how many real people in Mexico beyond the 130,000 on track today are covered by new policies, how widely CONAES can expand its membership and address broader sectors of the economy, and how sustainable its partnership with government and the NGO community becomes over the long term.

Case Study 2: The International Code of Good Practice for NGOs responding to HIV

Prepared by Julia Cabassi, author of the Code

On World AIDS Day, 1 December 2004, *Renewing Our Voice: Code of Good Practice for NGOs Responding to HIV*¹² was launched in ten countries, with the endorsement of over one hundred and sixty NGOs from around the world. Julia Cabassi¹³ examines the process of the developing the Code and considers the progress and challenges in ensuring its widespread implementation.

Why a Code?

Since the late 1990s there has been growing momentum to address the global HIV crisis, more so than at any other time in the course of the pandemic.¹⁴ There have also been significant changes in the global funding environment. These changes have brought fresh hope, but also very real challenges, particularly in ensuring that the significant body of evidence about how to respond effectively is used to guide the allocation of resources and inform programmes. There has been a considerable increase in the range and number of non-government organisations (NGOs)¹⁵ responding to HIV. While this is clearly welcome, there is a sense that this proliferation has sometimes occurred at the expense of accountability and quality programming and has fragmented the NGOs advocacy 'voice' in the response.

NGOs leaders from around the world considered these challenges at a civil society meeting in November 2002. A strong consensus emerged about the need for a code of practice that would enable NGOs to commit to a shared vision of good practice in responding to HIV. A steering committee was formed to take the initiative forward, comprising some of the most experienced humanitarian, development, health and NGOs working in HIV.¹⁶

It was envisaged that a code of practice would:

- outline and build wider commitment to principles and practices, informed by evidence, that underscore successful NGO responses to HIV
- assist NGOs to improve the quality and cohesiveness of their work and their accountability to their partners and beneficiary communities
- foster greater collaboration between the variety NGOs now actively engaged in responding to the HIV pandemic, and
- renew the 'voice' of NGOs responding to HIV by enabling us to commit to a shared vision of good practice in their programming and advocacy.

The idea of building global consensus among NGOs about a set of good practice principles to guide their work was certainly an ambitious undertaking. This was particularly so given the intention was to seek formal endorsement by NGOs so that the Code would represent an authoritative and credible statement from the NGO sector. There was a fear that failure to achieve a critical mass of support across the diverse range of NGOs had the potential to polarise the sector, rather than foster cohesion.

However, lessons from the experience of other global interagency initiatives such as the Sphere Project's *Humanitarian Charter and Minimum Standards in Disaster Relief* indicated the enormous potential for a code to support consensus building about what constitutes good practice and through this, foster sector cohesion among a diverse and growing array of partners.

The development of a code provided a vehicle to:

- act on a genuine commitment among many NGOs to ensure that resources were used effectively, both by NGOs and by donors and governments
- demonstrate independence by funding the development of a code of good practice by and for NGOs, free of the constraints of government policy and
- draw upon the collective experience of the range of NGOs responding to HIV – HIV, sexual and reproductive health, development and humanitarian NGOs.

“Never has it been so important in the history of HIV to return to first principles. Despite our efforts the pandemic continues to outstrip us, despite 20-plus years of programming we continue to let ideology rather than evidence drive the design and implementation of our response and despite the growth in community interest and political will to fight the disease, we aren't doing nearly enough. Supporting the principles contained in the code and using it to enhance the quality and scope of programming will play an important part in meeting these challenges head on”.

Dr Nafis Sadik, the UN Secretary General's Special Envoy for HIV in Asia.¹⁷

Developing the Code: A policy process

“The Code is aspirational. By signing up to it we've committed to striving to improve what we do. The process of developing the Code created a sense of ownership that has made the Code a policy document that's alive. It's being used to guide concrete action.”

Manoj Kurian, World Council of Churches

The process of developing the Code was critical to its success. It provided the opportunity to discuss and debate what good practice is, to reflect on the evidence about what has worked and created the space to recognise the extent of the common ground among a wide range of NGOs. The process engendered a sense of shared ownership in the Code that is reflected in both the significant number and diversity of NGOs that signed on to the Code and the early indications about how the Code is being used by NGOs.

The consultation process

A draft outline of the contents of the proposed code was prepared and the idea tested with NGOs through a series of consultations during late 2003.¹⁸ This informed the development of the first draft of the Code, which was released for comment in March 2004 and used as a tool to engage the wider NGO community around the world.

The draft Code and accompanying briefing materials were made available in English, French, Spanish and Russian and input could be provided in any of these languages. Inputs on the draft were provided through participation in consultations meetings and by written submission. The eleven Steering Committee organisations played an active role in disseminating the draft Code and taking advantage of a wide range of meetings and conferences to gather and synthesise input on the draft Code. Seven formal consultation meetings were convened during March and July 2004, culminating in a satellite session at the XV International AIDS Conference in Bangkok.¹⁹

The Steering Committee was responsible for agreeing on the final content of the Code. The revised Code was widely circulated so that NGOs could consider whether they wished to 'sign on' to the Code. The revised Code was accompanied by a document that summarised the key issues emerging from the consultation process, the main revisions in the final text and the Committees' rationale for its decisions.²⁰

In order to finalise printed version of the Code for launches on World AIDS Day 2004, a period of only three weeks was available to submit a letter endorsing the principles in the Code signed by the head of the NGO concerned. In that brief period over one hundred and sixty NGOs did so. Many more NGOs have also indicated their intention to sign on the Code when an on-gong mechanism for signing on to the Code is established. (See Model for implementation the Code: a work in progress below).

Consensus building

There is no doubt that there was considerable interest in and support for the idea of a code. However, the idea also provoked some fears and scepticism, particularly in the early stage of the process. Fears were expressed about what increased accountability might mean, concerned that the code would imposed, as be a 'top down' exercise, despite the fact that it was made clear from the outset that the Code would be voluntary and NGOs would be free to decide whether they wished to sign up to it.

"AIDS has two faces, one face is fear and suffering and the other is the wealth and opulence of some stakeholders who profit more than they serve in the HIV response. It is usual to hear on the radio 'AIDS feeds more than it kills'. The code provides a common advocacy tool that different NGOs can use to ensure real and effective responses."

Baba Goumbala, Executive Director of Senegal's National Alliance Against AIDS (ANCS).²¹

There was also scepticism about whether the process would contribute to building consensus among a diverse range of NGOs, including faith based organisations (FBOs) or whether it would be divisive, particularly in relation to key issues such as the critique of the Abstinence, Be faithful, Condoms (ABC) approach, and the extent to which such an approach fails to recognise and address the societal factors that shape vulnerability to HIV infection²² and the importance of providing and/or advocating for comprehensive harm reduction programmes essential to effectively address the risks of HIV transmission among people who inject drugs, including access to sterile injecting

equipment and treatment for drug dependence, including substitution treatment such as methadone.

Precisely because the draft Code touched on sensitive and topical issues, NGOs and a wide range of other stakeholders actively engaged in commenting on the draft code through the range of mechanisms for doing so.²³ The process was designed to support engagement that could lead to consensus by:

- bringing together steering committee organisations that together had a vast network of member or partner organisations from around the world and with that opportunities for maximising input to the development of the Code and through it build support for the value of a code in strengthening the NGOs role in the HIV response
- investing time and resources in the consultation process such as designing and conducting face to face consultations that were conducive to dialogue, translations of draft code and mechanisms for input in five languages and
- an open, clearly articulated and transparent consultation and sign on process.²⁴

The Code, in its revised form, was markedly improved and far richer for the contributions made through the process. It is clear from the diversity of NGOs, including FBOs, that signed on to the Code, that the process did build consensus around, and clear support for, an evidence based approach.

What the Code covers

The Code consists of guiding, organisational and programming principles. The *guiding principles* – core values, human rights, public health and development principles – provide the overarching framework for the Code.

The *organisational principles* provide guidance on good practice to guide *how* NGOs work areas including:

- involvement of people living with and affected by HIV
- multi-sectoral partnerships
- good governance and organizational management
- programme planning, monitoring and evaluation
- advocacy
- research

The *Programming Principles* provide guidance for mainstreaming HIV within sexual health, development and humanitarian programmes and HIV specific programming including:

- HIV prevention
- voluntary testing and counselling
- treatment, care and support
- addressing stigma and discrimination.

The Code provides the evidence base for each principle and key resources such as tool kits and manuals that can assist NGOs in putting the principles into practice.

What could the Code be used for?

“Do we too benefit from what we see today as the HIV industry? It has become abundantly clear that effective scaling up requires coherence and coordination in-country. It is imperative that every dollar is well spent and focuses on making a real difference in people’s lives. I hope the Code will enable NGOs to become valued partners in their own countries so they could influence national AIDS plans and funding decisions by their own governments.”

Razia Essack-Kauaria, governing board member of the International Federation of Red Cross and Red Crescent Societies and Secretary General of the Namibian Red Cross. ²⁵

It was anticipated that the principles set out in the Code could be used in a wide variety of ways including to guide:

- organisational planning
- the development, implementation and evaluation of programmes, including advocacy programmes
- advocacy efforts, particularly with donors and governments, to promote evidence based programme and allocation of resources based on the principles it outlines.

Signing on to the Code: Commitment and action

The ground swell of support for the principles outlined in the Code, represented by number and diversity of NGOs signing on to the Code, enhances the credibility of the Code and adds weight to its use as an advocacy tool. Nonetheless, the real test of the value of the Code lie in the extent to which it is effectively implemented. Indeed, an additional function of the formal ‘sign on’ mechanism was to be able to identify and work with a defined group of NGOs that support and use the Code in order to be able to collect, analyse, and disseminate information on the impact of the Code through its implementation.

Model for implementing the Code: a work in progress

In determining the model for sign on and implementation of the Code, the Steering Committee commissioned an analysis of the models for sign-on and implementation used in relation three inter-agency codes by other networks in the aid sector.²⁶ That report concluded that without a significant investment, the Code is likely to remain a work of reference rather than a catalyst for change.²⁷

The Steering Committee decided to establish a secretariat to support implementation of the Code. It is envisaged that the secretariat will:

- provide a focal point for marketing the Code, providing information about and a process for other NGOs that wish to sign-on to the Code
- support signatory NGOs as they use the Code in their work
- act as clearing house for documenting and disseminating information about implementation of the Code.²⁸

The Steering Committee has commenced planning for this second phase of this project, but has not as yet secured the necessary funds to commence phase two. In order for the Code to move beyond being a statement of intent to a tool for greater accountability and principles that shape action it is essential that NGOs can demonstrate how its use is having improving practices.

How is the Code being used? ²⁹

Despite slow progress in commencing the phase two – supporting implementation of the Code – a wide range of players, including the committee, signatory NGOs and other stakeholders have taken the initiative to maintain the momentum by promoting the Code in their networks and using the Code in their work.

Advocacy for effective resource allocation

Common advocacy tool for evidence based resource allocation in Senegal

The ***Observatoire de la réponse au VIH au Sénégal*** (the Observatoire) was established to strengthen the role of civil society in decisions about resource allocations and advocate for greater transparency in the use of Global Fund and World Bank funds in Senegal. The Observatoire is a collaboration between organizations already working in the response to HIV (ANCS, Africa Consultants International, ENDA Santé, SIDA Service and Synergie pour l'Enfance). The Observatoire targets and involves a range of actors responding to HIV in Senegal, including government, development partners and civil society organisations. It has two roles:

- a national watchdog, by critically examining the multi-sectoral response
- a forum to reflect and make recommendations.

The principles set out in the Code are central to the work of the Observatoire and it is used as a common tool to guide their advocacy work, particularly in advocating for the establishment of guiding principles for a multi-sectoral response to HIV in Senegal and ensuring evidence informs programme priorities for the national response.³⁰

Influencing International NGOs as donors

Shaping principles that underscore the work of Danish International NGOs

AIDSNET - The Danish NGO Network on AIDS and Development – is a network of nineteen NGOs and two research institutions. It was established in 2000 as a platform for knowledge sharing among NGOs in order to strengthen the capacity of NGOs to address HIV prevention, care, support and treatment in developing countries. The Code came just at the right time for AIDSNET, when there was a growing awareness among network members about the need to articulate the values and principles that underpin their work.

"We needed some kind of an input to stimulate our thinking and reflect on how to turn the idea of a statement of principles into a more systematic and comprehensive framework for AIDSNET." Lise Rosendal Østergaard, AIDSNET, Coordinator

AIDSNET held a forum in August 2005 to introduce the network members to the Code and explore how the principles in the Code could assist the networks and its' members in doing so. The AIDSNET Executive is considering how to take that discussion forward.

Guiding organisational planning

Guiding development of ActionAid International's HIV strategic plan

In May 2005, **ActionAid International** (AAI) held an HIV convention in Nairobi that brought together staff and partners from across the globe to guide the development of their five-year International HIV&AIDS Strategic Plan 2005 - 2010. The convention drew on the Code to inform lively discussions, particularly focussing on mainstream HIV across the whole spectrum of the rights based work they do – in education, food, women's rights, human security in conflict and emergencies and just and democratic governance. The Plan specifically draws on the principles in the Code, and in so doing provides the starting point for AAI's commitment to implement the Code in their work.

Shaping organisational policy and practice

Catalyst to concrete action within faith based communities to support meaningful involvement of PLHA

The Code has provided a tool for internal advocacy within the faith based sector. Signing on to the Code has been a catalyst for the **World Council of Churches** to work to improve their efforts to meaningfully involve people living with HIV (PLHA) in their organisation, and their work, as well as to advocate and support their member organisations to do so. They are employing a range of strategies to do so including developing and promoting a framework for engagement of PLHA within the faith based communities; compiling a compendium of church commitments in relation to HIV for use as an advocacy tool; developing and promoting an HIV workplace policy; and concrete measures to involve, fund and resource PLHA to be involved in key events of the World Council of Churches.

Case study 3: National Policy - The Australian response to HIV

Prepared by Lou McCallum, former head of the Australian Federation of AIDS Organisations, describes the national policy environment in Australia that has given rise to a set of stable and productive partnerships.

The Australian national response to HIV has been a particularly successful one, characterized by strong and consistent political leadership, civil society participation and consistent policy.

The response has been underpinned by a series of five-year National AIDS Strategies that have formalized a set of guiding principles, allocated responsibilities and resources and defined the approach to be taken in a range of areas.

The broad acceptance of these National Strategies has supported the creation and maintenance of an enabling environment for HIV prevention and care that has resulted in a steady decline in the number of HIV infections detected, a reduction in HIV-related stigma and discrimination and the provision of universal access to treatment, care and support for people with HIV.

The characteristics of this national response have been described in many publications. This case study will focus on an examination of the set of key partnerships that have emerged from the National Strategies and that have contributed significantly to the success of the national response.^{31,32}

Australia took some time to develop a comprehensive approach to HIV. The first person was diagnosed with AIDS in November 1982 and hospital and community services were soon under pressure as the number of people diagnosed increased steadily. The primary modes of transmission were sex between men (accounting for more than 80% of cases) and the sharing of equipment associated with injecting drug use. Gay community, sex worker and injecting drug user organizations began HIV health promotion initiatives amongst their communities and national and state governments agreed on mechanisms to share the cost of programs.

The public health policy environment in Australia is complex. The national government is responsible for national laws and policies, for collecting most taxes and allocating resources to the state and territory governments for health, education and other services. The state and territory governments run most of the public health services, under policies set by themselves and by the national government. There is a range of civil society organizations at national and state and territory level that lobby on behalf of the communities or groups they represent and these organizations contribute to policy development. The medical profession is represented by a range of professional organizations that also contribute significantly to policy development.

Despite certain movement forward in the response to HIV, debates about the most appropriate approaches to take raged. There were fears that the epidemic would 'cross over' from the gay and injecting drug user communities to the general community and

proposals that people with HIV be either isolated or at least have their behaviour limited in some way to protect the health of the wider population.

In late 1987 the national government decided to embark on a process to develop a national strategy that would provide some stability and consistency in the response to HIV. Rather than hastily produce a document and expect the complex array of interested parties to agree to it, the government made a deliberate choice to slow the process of policy development down and embarked on a national consultation to provide an opportunity for community discussion of the range of available approaches to HIV.

A Policy Discussion Paper (Green Paper) was developed, proposing a set of objectives and guidelines for the national Strategy and setting out the policy considerations for a range of relevant issues. This Green paper was tabled in the national parliament and in all state and territory parliaments to ensure ownership and bi-partisanship. Briefings were then held for each state and territory parliament and the Green Paper was circulated widely for comment. Six panels of key interested individuals were formed and toured the country holding public meetings. Feedback from this process was incorporated into the five-year National Strategy, which was launched in all parliaments in August 1989.³³

The principles of the Strategy:

The first National AIDS Strategy set out principles and guidelines that have endured and have been contained in subsequent strategies. They are summarized as:

- A national strategic approach
- An enabling environment
- Non-partisan political support
- Health promotion and harm minimization
- The partnership approach
- The involvement of affected communities
- Linked strategies (to the Indigenous Sexual Health Strategy and the national Drug Strategy in particular)³⁴

The expression of partnership:

One of the most enduring and successful elements of the Australian response to HIV has been the development and nurturing of partnerships as a central element of the response. These partnerships have taken several forms and have provided space for many individuals and groups to contribute to the response to HIV in Australia. The system of partnership has provided stability; provided structures and processes for the debate of issues; given community organizations a clear role, resources and legitimacy; shared power between governments, professionals and communities in a new and interesting way; and, created an environment in which the contributions of many diverse groups and sectors are respected and encouraged.

The other key result of the partnership approach is that it gave the community sector a legitimate place in the response and provided it with resources to work on health promotional and care and support in communities affected by HIV. Community

organizations at national and state/territory level became key players in these areas and in the setting and review of policy. They acted as an affected bridge between government and the marginalized communities affected by HIV – gay men, sex workers and injecting drug users. The acceptance of a notion of partnership meant that the organizations representing these communities and groups had resources and authority in the response.

Partnerships between governments and affected communities

Perhaps the most striking partnership has been between government and the communities affected by HIV. Community organizations have been funded by governments at national and state/territory level and have been given responsibility for health promotion and community care and support. They have been staffed and governed by people from within the affected communities. Their intimate knowledge of community norms and values has enabled them to respond quickly to changes in risk patterns in their communities and to respond with appropriate health promotion interventions. Their knowledge of the whole context of risk within their communities has helped them to build up cultures of safety that support the decisions made by individuals to avoid HIV infection or prevent transmission. A strong example of this has been the Positive Sex initiative by the National Association of PLHA (NAPWA) that took on the difficult issue sex for people with HIV.

The existence of this partnership between governments and the affected communities had a significant impact on the way that civil society groups participated in the response. Having access to resources and to the decision-making processes for policy and national programs meant that civil society groups became part of the response and could resolve policy issues with minimal confrontation. This led to a different set of rules of engagement with government. There were still times when civil society groups and governments found themselves at odds over policy issues, but there were many more times when issues could be resolved relatively easily through the mechanisms of partnership.

Partnerships between sectors

The HIV response in Australia has been steered by a national committee which has taken on many different forms and names over the years. It has generally been made up of politicians, people with HIV, community group leaders, senior public health clinicians, health promotion experts, human rights lawyers and others. It has symbolised the partnership approach and been the body for setting and overseeing the review of policy. It played a role in advising government and in protecting the health minister from direct blame for some of the controversial policy decisions that Australia took in its response to HIV.

Partnerships between governments:

Parliamentary Liaison Groups (PLGs) were used effectively as a place for politicians from different sides of government to express their views and debate issues. The members of these PLGs became advocates within their political parties for the approaches adopted

under the National Strategy and were in the best position to shore up support for these approaches within their parties.

An Inter-Governmental Committee on AIDS, which brought together senior health bureaucrats from national, state and territory governments, has provided a forum for pragmatic discussion and resolution of funding issues, policy clashes and differences in approach from state to state. Many issues were resolved quietly by this group, away from the political spotlight.

Partnerships between groups affected by HIV

The ability of people from gay communities, sex worker groups, injecting drug users and people affected by transfusion-related HIV infection to work together has been a particular characteristic of the Australian response. A national HIV NGO - the Australian Federation of AIDS Organisations (AFAO) - was established early in the epidemic and remains strong and vibrant today. Its members were the national organizations of PLHA, sex workers and injecting drug users and the state and territory AIDS Councils – NGOs established at that level to oversee the community response. Despite the different perspectives of these groups, they have been able to present coherent and consistent policy positions to governments and have shared skills and resources across their network.

Partnerships between researchers and affected communities

Community groups and researchers have developed a set of constructive partnerships that have guided the response. The government provided funds for the establishment of national research centres in HIV social research, clinical research, epidemiology and virology. These centres set up clear mechanisms for community participation in the design and implementation of research and in the dissemination of findings to assist in program review.

This has been of great assistance to both researchers and community groups. Working in collaboration, researchers and community members designed research that answered the pressing questions that were affecting the implementation of programs. Community members took the results of this research back into their program review sessions and back to community. This all happened in a timely manner and meant that community programs were responsive to changing context and risk patterns.

New partnerships of this type led to the development of national guidelines for consumer participation in research that apply beyond HIV to all health research.³⁵

Partnerships between health services and affected communities

In the early part of the epidemic, little was known about HIV transmission and hospitals had little experience in providing supportive services for people from marginalized communities like gay men, injecting drug users and sex workers. Many of the hospitals in the most HIV-affected areas asked people from the organizations working within these communities to join their care teams to provide support and counseling to PLHA.

As PLHA organizations began to form, members of these groups also became part of care teams and advisory groups. This was an unusual step for health services that had previously been relatively closed to community participation of this type and it led to the development of different forms of participation that continue to increase the accountability and quality of health services for these groups.

Conclusion:

The presence of a consistent set of HIV policies in Australia has provided a stable base for a consistent response to HIV. The response has always been vibrant, with plenty of debate and disagreement, but the policy environment has generally provided a space and mechanism for discussion, constructive engagement and resolution.

Case study 4: An organizational policy: The Salvation Army

Prepared by Meble Birengo, Community Worker, Salvation Army, Kenya

My name is Meble Birengo, born on the 12 December 1980 in a little township called Bungoma which is on the Western part of Kenya. I have worked with The Salvation Army East Africa Territory for the last five years, giving support to the developing of a Territorial Facilitation team, scaling up community Integrated Psychosocial Support for orphans and vulnerable children, mentoring and developing leadership in youth, children and communities as well as giving a focus to the Spiritual growth of young people that are engaged in the process. I have also been involved with the African Regional Facilitation team, strengthening the psychosocial support element across Africa, the International team as well as working with UNAIDS on the Self Assessment tool developed for HIV competency.

When I think of policy, I reflect on the ongoing work and responses of the Army in general. The belief, behaviour, approach and practice of people in communities is at the base of all of our work. This practice, that is not imposed but is stimulated by being alongside and walking with people, in retrospect, forms an invisible policy for ways of working. It is not really mentioned or physical but provokes a sense of knowing that there is policy present in the communities and strengths that exist at a community level. It is the basis and belief that has inspired me to share this pathway of my life.

The Salvation Army is an International movement, an evangelical part of the universal Christian Church. It is also an integral part of the Christian church, although distinctive in the way it is organized and in its practice it also follows the mainstream of a Christian belief. The approach that the Salvation Army has embarked on internationally regarding issues around HIV is the approach of Integrated Mission for Human Capacity Development. The belief is that people and communities have the abilities and capacities and enough grace to respond and act on their issues. I have been a witness of this response and a policy that has been put in place to strengthen communities in responding to concerns, not only on HIV, but in all areas of social injustice, orphans and vulnerable children (OVC), poverty, child trafficking and witchcraft. Human Capacity Development has been the Salvation Army's response and way of working since 1985, when health workers at a small hospital called Chikankata in Zambia realized that people were capable of taking care of their loved ones, and that they did a better job than the Doctors.

All they needed was an understanding and support to know that they can do it. The health workers began to go into homes to see and learn how communities were taking their own initiative to respond to caring for people and also supported the education of older and young women in the cleanliness of the homes. This act and behaviour led to a desire to form a facilitation team that would work as a learning but process thinking team for expansion of this informal way of caring and supporting families and communities. Now in over six countries in Africa, strong demonstrations are found that are providing learning grounds for this behaviour and approach. This belief has been established as a way of working for the Salvation Army in relation to HIV but also as a

way to provoke a wide response regarding care, change, leadership, hope, vision and response.

The Salvation Army's policy to responding to HIV as explained briefly focuses on the 'person' as the solution to all the issues, on the 'people' whose joint capacities and efforts enhance a fast outcome and on 'communities' where there is leadership and opportunities for mentorship and decision making hierarchies which are not governed by a recognized government, but by identified and influential people found within the communities. The Salvation Army's way of working has been through the facilitation team approach, where teams of people enter these competent communities to support and stimulate further thinking about life, to appreciate the strengths that exist, to learn from local communities and to transfer lessons learned and concepts of leadership, hope and change. This change is expressed through the uptake of caring of OVC and the desire for men to be involved in the struggle against HIV. *(See Transformed Together Video produced for the African Regional Facilitation Team)*

Working with The Salvation Army in this way has opened my eyes to realize that the world tends to think that problems are solved by giving communities things, being service providers, offering answers and building toilets for communities. But in a real sense, communities and people can do this for themselves. It's the 'how' we behave and the questions we ask that enable communities to respond. This understanding as a way of working for the Salvation Army has provided a sustainable grounding for our response, especially on the Leadership development for youth across the continent of Africa. Young people have realized their existing strengths and are now taking leadership in community processes.

The Salvation Army's policy of an integrated approach has supported the strengthening of existing community programmes. When people realize that they own a process and that they are acting according to their strengths, there is a sudden motivation for further action. The strength of our approach has been realized by outsiders and there is interest shown now by people to come and learn from Africa and a deliberate sensitivity to ways of living and working in the African communities; a realization that it's impossible to walk into an African community and start making decision. Building relationships, having several encounters, establishing trust and behaving in a sensitive way are the strategies for developing an entry point for a further engagement. Our approach is to sit with a bereaved family in a shady house on top of a hill, or talk to an old woman under a tree in a market place as she sells mangoes or to an old man seated on a small stool eating groundnuts as he watches his one cow graze. These kind of settings, where we engage in a conversation with people about the deep things in life, their vision and hopes, key things that worry and bother them or are concerns for them as people. Spending this time with people is an expression of care, healing and support. Asking these questions that provoke thinking is enough, and better than giving answers to people's problems. This approach actually reduces the stress and pressure on us for wanting to fix things.

Knowing that there is an understanding amongst us on our approach in the communities we encounter, even if it is an informal and unmentioned set guidelines, has been an entry point for me to find better ways of working with children and young people. This deliberate sensitivity towards strengths of people has been a stepping-stone for my own

development in working with youth. Since 2002, my understanding of strengths, vision and Integrated Mission has deepened, and enabled me to scale up the youth responses from a starting number of fifty, to three thousand children and youth over a period of three years. As well we have been able to scale up an integrated response for OVC in Kenya and in Uganda from five targeted Divisions to fourteen Divisions, four of which have been an informal transfer of concept, where I had nothing to do with the transfer. It happens as the needs and desires arise from the neighbouring communities who wanted to see change happen for them.

The biggest challenge we have faced so far, is the fact that the scale of loss is so high. It could be compared to a tsunami every ten days. Mourning is becoming a long lost moment. Africa is a continent where bereavement and mourning has always been a way of strengthening family bonds and renewing old relationships. When someone dies, all of the children who are overseas or in big cities will come for fellowship. But as a result of HIV, the family bonds are being torn apart, and the existing social networks are less, leaving children to become heads of households. Amidst all this, the fact that people still wake up and visit their sick relatives and neighbours, fetch water for sick homes or feed and take in orphans left behind will forever remain an invisible attitude of care and response in homes. It is these unmentioned policies in African communities that make Integrated Mission an approach for a sustainable response for people, communities and facilitation teams.

KITHITUNI COMMUNITY: An Example Community of Existing Policies for Response:

One of the communities that has become a strong example for others in East Africa Kenya is Kasikeu-Makueni District or Kithituni. Kithituni is found in the lower semi-arid region of Kilome Constituency, Makueni District, and Eastern Province in Kenya. This area can be reached through the Nairobi-Mombasa highway. Because of its location near this highway, there is high promiscuity, predisposed by the presence of commercial sex workers and the high influx of truck drivers. This has aggravated the menace of sexually transmitted diseases and HIV transmission. Moreover, the area is remote because of its physical isolation and under-development.

Kithituni is one of the communities that has grown to respond strongly through the concept of community to community transfer stimulated by Major Rebecca Nzuki, a Salvation Army officer who had been previously working in Kibera - a poverty stricken urban community in Nairobi. With the help of the Territorial Facilitation team and the support from the Regional Team, Kithituni community began to respond and transferred the concept to 54 other communities in five years. Rebecca was transferred to Kithituni in 2000 and she developed a facilitation team using the local congregation of the Salvation Army. She and the team began to visit people in their homes and during market days, asking them what issues they were dealing with. They also asked what people were doing regarding the ongoing issue of HIV and increase of widows in Kasikeu. The facilitation team grew in number as members of the community became interested in joining in the discussions. The facilitation team expanded their response from one community to around 54 communities. Some of the community owned responses that arose as a result of this way of working were:

- Widows began an Income Generating Activity, rearing goats, selling them to purchase books, pens and even clothes for orphans, and also a chicken-rearing project, a basket-making project.
- PLWA came together and began a bead-making project. They sell the beads to make money to support their families.
- People began to talk openly about HIV.
- Men began to be more involved in the response for OVC and became faithful to their wives.
- Men stopped beating their wives because of fear from the neighbours who became watchdogs for the protection of battered women and abused children.
- Chiefs and local leaders became involved in all the community counseling sessions under oak trees facilitated by the facilitation team.
- They are running a business and are using the money to support Orphans through high school.
- More young people active in the church and in the home visits and are competent in the process and the behaviour of learning. They have extra eyes of seeing strengths and capacity, rather than problems and challenges.
- Young people are taking leadership in the working with children through the psychosocial support concept, using play therapy as an entry point for discussions on bereavement and leadership development
- Other programmes include community based rehabilitation, home-based care and a 'one million shillings through the one million friends' concept. This vision is sparked by young people.

Their capacity has led to them visiting countries like, Mozambique, Rwanda, Nigeria and in India to provide a sharing for discussion in an international conference towards harmony, conflict resolution and reconciliation between young people from Kithituni, India and Australia. Young people have become the agents of change and stimulants of response in Kithituni. Through the support from various people in The Army, Kithituni youths have become competent self-motivators to strengthen their community. They are heading the HIV response process and responding to care for OVC through Kids and Youth Clubs as well as using dramas to engage in conversations with the wider communities. They are running a process that is aimed at sponsoring orphans and following up children in homes and families linked to the ongoing community work.

In Kithituni *"There is virtually no one who does not have personal experience of HIV. If the pandemic has not touched their own families, it is more than likely to have taken friends or neighbours"* says Onesmus a 24 year old young man who is heading a household and taking leadership in the Mentoring of other young people in Kithituni.

The magnitude and impact of HIV in Kithituni and Kenya at large is not just a major public health problem and development but increasingly creating a negative impact in all aspects of our lives. The empowerment of communities has been the key answer to grassroots to respond better to the concerns in the communities, this is the approach that The Salvation Army in Kithituni has embarked on, to empower communities that they can make their own decisions through support teams that stimulate, support and share experiences. Kithituni community is committed to respond efficiently to the necessities of these poorest communities by promoting community participation through

sensitization and mobilization in order to take responsibility for their own development, decision and capacity building. This will embrace values to care for one another: "Hope for a healthy future and respect for human life".

Case study 5: A partnership between farm workers and land owners - Namibia

Prepared by Deborah Bickel, POLICY Project, Futures Group, Washington

The southern African country of Namibia is burdened with a profound inequity in the distribution of income inherited from its recent colonial past. According to the World Bank it is currently the least equitable economy in the world. It is also experiencing a devastating HIV epidemic, again ranking with the top five countries in sero-prevalence according to the 2004 UNAIDS report on the global epidemic. Driving along its super highways, through gorgeous national parks and well developed cities and towns, it is hard to reconcile those harsh realities with the sense of prosperity that greets the casual observer or tourist.

Namibia is rich in natural resources with diamonds and uranium sales underpinning its diverse mining industry. Agriculture is the second largest economic base, with about 4,000, mostly white, commercial farmers owning nearly half of the arable land. In nearby Zimbabwe with a similar history of inequitable land distribution, impatience with the slow pace of land reform has led to whole sale land seizures resulting in economic chaos in a country previously known as the 'breadbasket' of eastern and southern Africa. Namibian land owners are viewing this scenario nervously and hope that the government acts decisively before the country erupts into violence over inequitable land and asset distribution.

Added to this troubling mix, the HIV epidemic is hitting Namibia particularly hard and continues to have far reaching effects on the labor force, and most particularly on agricultural workers, who are the majority of all workers in Namibia (70%). Many agricultural workers work only seasonally and undergo long periods of time away from homes and family, raising their risk of exposure to HIV. They also benefit least from recent labor reform acts guaranteeing minimum wages and provision of adequate health and safety measures.

Most health and social services available to farm workers are privately provided, usually by farm owners and employers with limited government support or oversight. This leaves farm workers dependent on the fair practice and goodwill of corporate or individual land owners for their well being. These services, when offered, add to the rising cost of labor in the competitive global market. The impact of poor land distribution and the rising cost of HIV services place an extraordinary burden on a government trying to provide effective and fair legislation and policies.

The Namibian government's response to the epidemic and to issues of land reform is vital to the nation's survival and the wellbeing of its workers. The effects of HIV on the economic and social fabric of the country are so profound. Addressing HIV in Namibia has required a focus on key governance issues of human rights and equity, the same issues at the center of the land tenure struggle.

The Ministries of Labor and Health are currently making a great effort to engage all sectors of government in the development of strategies and effective responses to HIV. These include the development of workplace policies and programs that provide care, prevention and support for affected workers and their families. The push for prevention and care services in the workplace is accompanied by a recent reform in the Labor Act that guarantees workers' rights to safe worksites, as well as reasonable accommodation and medical support for those affected by HIV.

Against this backdrop, the Namibian Ministry of Labor, with support from the US Department of Labor, initiated a project to develop a HIV workplace policy for the commercial agricultural sector. The project also includes support to individual organizations, businesses and farms in the drafting of company-specific workplace policies. Extensive consultation and mediation with the two primary unions representing farm workers and farm owners in the commercial agricultural sector has occurred over the last two years. These meetings resulted in a mutually-agreed policy reflecting domestic and international labor legislation and standards.

In a volatile environment of fear and mistrust generated by land distribution inequities, traditional adversaries representing farm owners and workers came together to devise a sector-wide workplace policy addressing HIV. Consultative meetings were held in many parts of the country and members of the AIDS Law Unit served as mediators. This resulted in the signing of a comprehensive HIV policy for the commercial agricultural sector in September 2005.

The policy development process offered an opportunity for workers to talk with owners about working conditions, fair labor practices and their more personal frustrations, fears and hopes. It also provided an opportunity for farm owners to speak frankly about the very real economic limitations they face in order to effectively compete in regional and global markets. The presence of external mediators from the AIDS Law Unit served to keep both parties at the table, lent legitimacy to both perspectives and supported respectful consideration of conflicting concerns.

Discussing the principals underlying the HIV policy provided an opportunity to re-examine rights and obligations of workers and management in a human rights framework. The same processes, language and values are the cornerstones of effective land reform. The ensuing frank and often fractious debates over the rights and responsibilities of the respective partners mirrored the broader political debate in the region over worker rights, land tenure and responsibilities of land owners.

Futures Group and Project Hope held a series of workshops to assist individual farming operations to develop site-specific HIV policies. These workshops provided an opportunity to observe the struggle between farmers and farm workers at first hand. Farm owners and their representatives had an opportunity to describe the risks and personal cost of running a farm in lean or unstable times. Workers were able to give voice to their frustration about low wages, distance to health care services and absence of basic first aid precautions to deal with work-related accidents.

In some of these workshops, workers reported feeling devalued by land owners, who they thought made little effort to speak in a shared language. They felt that landowners were impatient with the slow process of drafting meaningful and realistic workplace policies with newly literate workers. Farm owners reported frustration with worker reluctance to speak in front of a group or to ask or answer direct questions. Misunderstandings were frequent, but on most occasions discussed and resolved. Every farm that initiated the policy development process was able to agree upon a final draft that conformed to the International Labor Union standards, as well as current Namibian labor laws.

Policy drafting forums at the sector level, as well as at the local farm site, introduced owners and workers to international standards of ethical corporate behavior. A representative of management on one farm described an increased pressure on growers to guarantee the health and safety of workers, in line with the ever more rigorous standards of hygiene and fair labor practices demanded by international buyers associated with the European Union. For example, in the southern farming community of Aussenkehr, buyers for a large Dutch chain of supermarkets visited all farm sites that they buy from and assessed water and waste management systems. If a farm did not meet their standards, the company did not purchase that farm's harvest.

For land owners in Namibia there is a growing realization that their economic survival is contingent upon maintaining good relations with their workers, as well as answering to a strong judicial system and government commitment to rule of law. Addressing workplace HIV issues with a commitment to the wellbeing of workers can provide an opening for dialogue on other issues vital to the survival of the agricultural sector. This dialogue is fundamental to the creation of robust legislation and policies supporting and protecting fair and equitable treatment of all Namibian citizens, whether workers or land owners.

In July 2005 in Aussenkehr, while representatives of workers and management of a large farming concern sat across the table from each other to develop an HIV workplace policy, a fight between workers and owners over racial tensions and working conditions broke out at another farm across the valley. It resulted in severe injuries to two farm owners, one of whom lost his eye. This incident captures the tension underlying daily life in Namibia and the need for constructive dialogue between land owners and farm workers. The country's future rests upon how its present leaders respond to the dual challenges of an HIV epidemic affecting the entire labor force and equitable land and income distribution.

¹ McLean, S. What is Policy? Describing the HIV Policy Development Process, Australian Federation of AIDS Organisations www.afao.org.au

² Hardee, K., Feranil, I, Boezwinkle, J, & Clarke, B., The Policy Circle: A framework for analysing the components of family planning, reproductive health and HIV policies, The POLICY Project, 2004

³ Porter, R.W. Knowledge utilization and the process of policy formation, http://pdf.dec.org/pdf_docs/PNABX317.pdf

⁴ Kingdon, J.W., *Agendas, Alternatives and Public Policy*, Addison Wesley Education Publishers 1995

⁵ Better Government for Poverty Reduction: more effective partnerships for change, DFID 2003

⁶ Walt, G., Lush, L. & Ogden, J International organizations in transfer of infectious diseases policy: iterative loops of adoption, adaptation, marketing, Future Governance Paper 16, 2003 Economic & Social Research Council UK

⁷ Bridging Research and Policy in International Development, ODI Briefing paper no 1, October 2004 www.odi.org.uk/CSPP/docs/rapid_bp1.pdf

⁸ Kingdon op cit

⁹ Robinson, N 'Policy Studies: Theory and practice'

¹⁰ Networks for Development, UNDP Website <http://www.undp.org/hiv/publications/networks.htm>

¹¹ Education and HIV: a Window of Hope, The World Bank, 2002

¹² The Code, list of signatories and background papers, are available at www.ifrc.org/what/health/hivaids/code/

¹³ Julia Cabassi works as an international HIV consultant. Ms Cabassi was the Project Manager for Phase 1 of the NGO HIV/AIDS Code of Practice Project and is the author of the *Renewing Our Voice: Code of Good Practice or NGOs Responding to HIV/AIDS*. This article was prepared by her in an individual capacity and is not intended to represent the Project Steering Committee.

¹⁴ A significant example of this momentum is the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), held in June 2001, which resulted in the unanimous adoption by member states of the *Declaration of Commitment on HIV/AIDS* that set time-bound targets against which governments and the UN itself may be held accountable.

¹⁵ For convenience, the term NGO is used to encompass the wide range of organisations that can be characterised as 'not for profit' and 'non-government'. This includes Community-Based Organisations (CBOs), Faith-Based Organisations (FBOs) and organisations of affected communities, including people living with HIV/AIDS, sex workers and women's groups, among many others, who are active in the HIV/AIDS response. This is consistent with the language used in the Code.

¹⁶ The Steering Committee meet for the first time in June 2003. The International Federation of Red Cross and Red Crescent Societies hosted the NGO HIV/AIDS Code of Practice Project. The Steering Committee is ActionAid International, CARE USA, Global Health Council, GNP+, Grupo Pela Vidua, Hong Kong AIDS Foundation, ICASO, International Federation of Red Cross & Red Crescent Societies, International Harm Reduction Association, International HIV/AIDS Alliance and the World Council of Churches.

¹⁷ Dr Nafis Sadik, the UN Secretary General's Special Envoy for HIV/AIDS in Asia, in her open address at a forum to promote the Code, during the 7th International Conference on AIDS in Asia and the Pacific (ICAAP) in Kobe, Japan, July 2005. For full report of the forum see *Renewing the AIDS Response in Asia*, www.aidsalliance.org/sw28929.asp

¹⁸ Consultations workshops were held at the International Home and Community Care Conference in Senegal, November 2003 and the International Conference for People Living with HIV/AIDS in Uganda, December 2003.

¹⁹ Details about the consultation process are outlined in *About the Consultation Process* (See Background Documents), see web address in endnote (i) above.

²⁰ See the *Summary of Code Revision* in Background documents on webpage outlined above in endnote (i). The Summary provided:

- a mechanism for reporting back to stakeholders on key themes that emerged from the consultation process on the draft undertaken during the period March - August 2004 and
- transparency in the decision making process of the Steering Committee in determining the final text of the Code.

²¹ Baba Gumbala, presentation at the Code's symposium at the XV International AIDS Conference in Bangkok, July 2004. For full report on Code Satellite see Rosemary North, *Common Code for AIDS*

Response, full story on Code Satellite at the XV International AIDS Conference, Bangkok, July 2004 at <http://www.ifrc.org/docs/news/04/04071601/>

²² See discussion in relation to comprehensive HIV prevention, *Renewing Our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS*, pages 65 – 66, see web address in endnote (i) above.

²³ It is also important to acknowledge that the scope of consultations was limited by resource constraints. The Project was entirely funded by the Steering Committee organisations. Steering Committee organisations contributed \$242,000 USD to the Code Project budget and provided a further \$118,000 USD through in kind support, such as covering their own travelling costs to meetings, staff time and translating documentation.

²⁴ See for example: Background documents - About the Consultation Process; Summary of Code Revision; Options Paper: Sign On and Implementation and What will 'sign on' to the Code mean see web address in endnote (i) above.

²⁵ Razia Essack-Kauaria, presentation at the Code's symposium at the XV International AIDS Conference in Bangkok, July 2004. For full report on Code Satellite at the XV International AIDS Conference, Bangkok, July 2004, see web address in endnote (x) above.

²⁶ See *Options Paper: Sign On and Implementation* (Background Documents), see web address in endnote (i) above.

²⁷ The report found that other initiatives such as *Sphere* and *People in Aid* have shown that investment in small teams of staff and consultants have affected thinking, practice and advocacy in the NGO sector and beyond. See *Options Paper: Sign On and Implementation* (Background Documents), see web address in endnote (i) above.

²⁸ For details about the proposed approach to supporting implementation see *Renewing Our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS*, pages 91 - 93, see web address in endnote (i) above.

²⁹ As Phase 2 of the Project – Supporting Implementing the Code - is yet to commence, the examples of use of the Code are drawn from personal communications with the author and her own experience in working with NGOs to use the Code in their work.

³⁰ For further information about *Observatoire de la réponse au VIH au Senegal* www.aidsalliance.org/sw8225.asp

³¹ Bowtell, W 'Australia's Response to HIV/AIDS 1982 – 2005', Lowy Institute for International Policy www.lowyinstitute.org/PublicationGet.asp?i=289

³² Ballard, J Chapter in 'AIDS in Industrialized Democracies: passions, politics & policies', Rutgers University Press, 1992

³³ Reid, E. Speech given at..

³⁴ Australian National AIDS Strategy 1999-2004 , Aust Govt Publications Service

³⁵ Statement on Consumer Participation in Health and Medical Research, NHMRC, Australia, 2001. http://www.nhmrc.gov.au/publications/_files/r22.pdf