PANOS

Keeping the Promise?

A study of progress made in implementing the UNGASS Declaration of Commitment on HIV/AIDS in seven countries

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Acknowledgements

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Cover photos

Top left: The HIV/AIDS response in Haiti has received a lot of support from donors that has helped to improve the health infrastructure. This has enabled hospitals to administer ARVs to those in need and advance the health care of PLWHA.
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Top centre: Voluntary counselling and testing blood samples for HIV are two of the prevention services offered by civil society organisations. They are also heavily involved in offering care and support to people who are HIV positive.
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Top right: Ethiopia's orphan population, estimated at 720,000 in 2003, is the second largest in sub-Saharan Africa. The young girl in the picture is waiting outside a hospital, where her sole surviving parent is receiving treatment for HIV/AIDS.
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Bottom left: Latvia has a concentrated HIV/AIDS epidemic with high HIV prevalence rates among vulnerable populations such as sex workers and injecting drug users. These people experience stigma and discrimination, key barriers to be overcome in the response to HIV/AIDS.
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Bottom centre: A peer educator provides information about HIV/AIDS and sexually transmitted infections (STIs). Although demand for condoms is gradually increasing among vulnerable populations in Bangladesh, supplies are unavailable or irregular.
DAN WHITE | PANOS PICTURES

Bottom right: Many people now have access to antiretroviral therapy (ART), but there is still a significant shortfall in all the countries studied between the number of people living with HIV/AIDS who require ART and the supply of antiretroviral drugs available.
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Panos exists to stimulate debate on global development issues. Panos provides in-depth information on the social and economic causes and consequences of the HIV/AIDS epidemic in the developing world. In addition, Panos plays a key role in the development of contemporary approaches to HIV/AIDS communication.

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Abbreviations and acronyms

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
BCC	Behaviour change communication
BPMSG	Bangladesh Parliament Members Support Group
CCM	Country Coordinating Mechanisms
CECOSIDA	Centre de Communication sur le SIDA
CIDA	Canadian International Development Agency
CRS	Catholic Relief Services
DFID	Department for International Development
EMSAP	Ethiopia Multisectoral HIV/AIDS Project
EU	European Union
FHI	Family Health International
GHESKIO	Groupe Haitien d'Étude du Sarcome de Kaposi et des Infections Opportunistes
Global Fund	Global Fund for AIDS, Tuberculosis and Malaria
HAPCO	HIV/AIDS Prevention and Control Organisation
HBC	Home-based care
HIV	Human immunodeficiency virus
IDU	Injecting drug user
IEC	Information, education, communication
ILO	International Labour Organization
M&E	Monitoring and evaluation
MANET	Malawi Network of People Living with HIV/AIDS
MOH	Ministry of Health
MSM	Men who have sex with men
NACP	National AIDS Control (or Coordination) Programme
NAPHAM	National Association of People Living with HIV/AIDS in Malawi
NASP	National AIDS/STD Programme (Bangladesh)
NGO	Non-governmental organisation
OVC	Orphans and vulnerable children
PEPFAR	President's Emergency Plan for AIDS Relief
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
PNAC	Pakistan National AIDS Consortium
STD	Sexually transmitted disease
STI	Sexually transmitted infection
UN	United Nations
UNAIDS	Joint UN Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNGASS	UN General Assembly Special Session
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing
WHO	World Health Organization

Executive summary

In June 2001 a Declaration of Commitment on HIV/AIDS was agreed by 189 member states at a United Nations General Assembly Special Session (UNGASS) in New York. A review of progress is under way, led by UNAIDS. This report is the product of studies conducted by the Panos Institute in seven countries focused on the progress being made in implementing the UNGASS declaration. The seven countries are Bangladesh, Ethiopia, Haiti, Latvia, Malawi, Pakistan and Sri Lanka.

Each of these countries has some elements of an effective response to HIV/AIDS in place. In some cases, these existed before the UNGASS declaration was made and, in others, they have been introduced since that time. However, there is little evidence that the UNGASS declaration itself has had a direct effect on political commitment in the seven countries studied. Nevertheless, there are many examples of senior politicians supporting efforts to respond to the epidemic, particularly through speeches at special events. However, there is a need to be able to assess national political commitment more rigorously. Indicators proposed by UNAIDS to track policies in-country and national spending on HIV/AIDS are intended to do this.

A key issue relating to the HIV/AIDS response in the countries studied is that in almost all (with the exception of Latvia), the response is largely funded by donors. This has many problems associated with it, including perceptions that the response is donor-driven, that there is little country ownership and that it may be difficult to sustain the current level of response when donor funding ends.

There are considerable challenges to providing effective HIV/AIDS-related services in each of the countries. For prevention services, this report argues for moving away from a 'one size fits all' approach to one which is tailored to the type of epidemic a country is experiencing. Generalised sexual epidemics, such as those occurring in Eastern and Southern Africa, require a broad, comprehensive, multisectoral approach. However, such approaches are inappropriate for countries with low-level or concentrated epidemics. In such settings, a focused approach primarily among the most vulnerable sub-populations will protect not only members of that population but also everyone else in the country.

It might seem appropriate that there is stronger political commitment to responding to HIV/AIDS in countries with high levels of HIV prevalence among the general population due to the fact that these countries are experiencing the effects of AIDS-related illness and deaths. However, this risks other countries failing to take suitable actions at a time when the epidemic can be contained and reversed. This report argues for a different kind of political commitment in countries with low-level and concentrated epidemics that focuses on providing effective services to the most vulnerable populations, even if they are controversial. These include condoms for sex workers, men who have sex with men (MSM) and injecting drug users (IDUs), and drug substitution therapy and sterile injecting equipment for IDUs.

Although there has been progress in strengthening HIV/AIDS monitoring and evaluation (M&E) efforts in some countries, there is still much more that needs to be done. All HIV/AIDS policies and strategies should have M&E systems built in. The shift away from donor-driven M&E systems towards nationally owned systems needs to be accelerated. More financial and human resources will be required to make this possible. Existing M&E systems based on case reporting need to be supplemented by a sustainable system of regular surveys, particularly among the most vulnerable populations in low-level and concentrated epidemics. It is important that data from M&E systems should be used to shape and drive the national response to the epidemic.

Activities focused on treatment, care and support have been strongly focused on providing antiretroviral (ARV) drugs. Significant progress has been made, particularly in countries needing to treat large numbers of people. Nevertheless, the number of people in need of treatment but not receiving it still remains unacceptably high. Also, there is a significant risk that other essential services, such as the treatment and prevention of opportunistic infections and the provision of care and support services, could be overlooked if the focus on providing ARVs is too narrow.

An effective country response to HIV/AIDS requires the involvement of many stakeholders, including non-governmental organisations (NGOs) and the media. Currently, the main role conducted by NGOs is the provision of essential services, particularly where it is difficult for a government to provide those services, e.g. prevention services for vulnerable populations. However, the role of NGOs could be usefully expanded in the areas of advocacy, monitoring activities and participating in national bodies that coordinate and oversee the HIV/AIDS response.

The report concludes with a review of the supportive environment including HIV/AIDS-related legislation in each country studied and the problems related to stigma and discrimination experienced by people living with HIV/AIDS (PLWHA). Stigma and discrimination remain an everyday experience for PLWHA and members of vulnerable populations. The underlying reasons for this are examined in different settings, as well as the effects that this has on the national HIV/AIDS response and the types of measures that can be taken to address this.

Key points

- Most respondents reported that the UNGASS Declaration of Commitment had had little practical effect on the national response to HIV/AIDS
- In most countries, the national response is largely donor-driven. This raises significant questions about national ownership and sustainability
- Approaches to HIV prevention need to be tailored to the type of epidemic being experienced in a particular country and not based on a 'one size fits all' approach
- Countries with low-level and concentrated epidemics need as much political commitment to responding to HIV/AIDS as do countries with generalised epidemics. However, the focus should be on providing effective prevention services to those most vulnerable to the epidemic
- Although some efforts have been made to strengthen national M&E systems, these remain donor-focused and under-resourced
- Initiatives to scale up antiretroviral therapy (ART) have had some success although many people needing treatment still do not receive it. Other essential services, e.g. care and support, may have lagged behind in the effort to scale up ART
- Civil society organisations are providing essential services in many countries. They could do more in other areas, such as in monitoring and advocacy
- Stigma and discrimination are an everyday experience for PLWHA and members of vulnerable populations.

Background 1

Around 1.5 million people in Ethiopia are HIV positive and at the end of 2003 there were an estimated 720,000 children orphaned by AIDS. Ethiopia does not have a specific policy on orphans and vulnerable children but does refer to the issue in its national AIDS policy.
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UNGASS

In June 2001 a United Nations General Assembly Special Session (UNGASS) on HIV/AIDS was held in New York to *'review and address the problem of HIV/AIDS in all its aspects, as well as to secure a global commitment to enhancing coordination and intensification of national, regional and international efforts to combat it in a comprehensive manner.'* A Declaration of Commitment was agreed by representatives of 189 member states, calling for immediate action to be taken on the epidemic.

The review process

This report is the product of studies conducted in seven countries by the Panos Institute in collaboration with a consortium of civil society organisations. Each study sought to assess the progress being made by the country in implementing the UNGASS declaration and hear the views of stakeholders, including in particular those most affected, especially PLWHA. The studies also used information available from other organisations. This report seeks to pull together common findings and to highlight issues of particular relevance from the individual country reports.

The countries studied

The seven countries studied were Bangladesh, Ethiopia, Haiti, Latvia, Malawi, Pakistan and Sri Lanka. Three of these have generalised[1] HIV/AIDS epidemics among their general population. These are:

- **Ethiopia** – in 2003, adult HIV prevalence was estimated at 4.4 per cent. It appears that the epidemic was initially concentrated among sex workers and truck drivers but has now spread more widely. By the end of 2003, an estimated 1.5 million people were HIV positive. The epidemic is having a significant effect on life expectancy and the numbers of orphans and vulnerable children (OVC)
- **Haiti** – there is some evidence that HIV prevalence is declining. In 1993, adult HIV prevalence was reported as 6.3 per cent and, in 2003, it was reported as 3.1 per cent. In 2005, there were reported to be just over 270,000 PLWHA

1
A generalised epidemic is where there is an HIV prevalence in the general population of >1 per cent

- **Malawi** – in 2003, adult HIV prevalence stood at 14.4 per cent, which appears to have declined from 1998[2] figures. An estimated 900,000 people are HIV positive with 170,000 now in need of antiretroviral therapy (ART). Some populations are particularly affected, such as sex workers and those in prison. The epidemic is hindering Malawi's economic development.

Although the other four countries do not have generalised epidemics, there are varying levels of concentrated epidemics[3] among vulnerable populations. For example:

- Based on seroprevalence studies among vulnerable populations, **Latvia** has a concentrated epidemic among IDUs (22 per cent) and sex workers (16 per cent). MSM and those in prison are also significantly affected. An estimated 3,000– 6,000 people in Latvia are HIV positive
- In **Pakistan**, adult HIV prevalence is around 0.1 per cent. However, a recent study in Karachi reported much higher levels of HIV prevalence among IDUs (23 per cent), male sex workers (4 per cent) and *hijras*[4] (2 per cent)
- In **Bangladesh**, adult HIV prevalence remains <1 per cent but prevalence among male IDUs has risen from 2.5 per cent in 1998/9 to 4.9 per cent in 2004/5. Hepatitis C rates among the same population are over 70 per cent
- In **Sri Lanka**, the adult HIV prevalence is <0.1 per cent. However, because there appears to be no data from surveys among vulnerable populations, it is not possible to exclude a concentrated epidemic.

2
There are conflicting figures in the report: based on antenatal surveys, the figure is given as 35 per cent, whereas UNAIDS data (used in Figure 1.1 on page 6 of *Keeping the Promise? A study of progress made in implementing the UNGASS Declaration of Commitment on HIV/AIDS in Malawi*) gives a figure of 16.2 per cent.

3
A concentrated epidemic is said to exist if HIV prevalence exceeds 5 per cent in any particular sub-population.

4
Transsexuals

Leadership and political commitment 2

In Latvia, journalists complained that the government doesn't do much about HIV/AIDS. Instead it prioritises issues such as paying health and education staff and bringing down the cost of living. Across the seven countries studied, doubts were raised that the UNGASS declaration had had any effect on national responses to HIV/AIDS.
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The role of the UNGASS declaration

The UNGASS declaration has been immensely useful, both as an international advocacy tool and as a practical way of strengthening national M&E systems. However, despite hopes to the contrary, it does not appear to have been a major driver to action in any of the countries studied. This does not mean that positive changes have been absent. Indeed, in many of the countries studied, significant progress has occurred, although developments predated the UNGASS declaration and it was not possible to attribute these changes directly to it. Many of the people interviewed had either not heard of the declaration or did not know what it was about. For example, one journalist in Bangladesh said, *'Frankly speaking, I have heard about it but I am not aware about the content of this document…'* In Latvia, the document describing the National AIDS Programme explicitly refers to the UNGASS declaration. However, there is little sense among stakeholders that it made any difference to the response or that it is driving the national response to HIV/AIDS. On the contrary, a great deal of scepticism was expressed by respondents about the practical value of such declarations of commitment.

In many countries, high-level politicians have made political statements and speeches about the importance of the response to HIV/AIDS. For example, in Sri Lanka in 2004, both the president and prime minister spoke about the issue on World AIDS Day. In Haiti, the former First Lady spoke openly about HIV/AIDS and participated in UNGASS in 2001. The President of Malawi participated in a 'big walk' focused on raising HIV/AIDS awareness. Both he and the vice-president made numerous public statements on the issue. However, they have faced considerable barriers themselves. For example, the former vice-president, Justin Malewezi, explained how difficult it was to have *'a serious discussion about AIDS in the Cabinet as people thought I was being hysterical'*.

Some politicians have done more than just talk about AIDS and have modelled certain actions. For example, in Ethiopia, the Mayor of Addis Ababa, the wife of the prime minister and a government minister all publicly tested for HIV.

Several countries have high-level political structures in place which are relevant to HIV/AIDS. For example, in Pakistan the parliament has a public health committee which includes HIV/AIDS issues within its remit. However, it appears that this committee has not yet discussed the topic at national level although similar structures have done so at provincial level. In Malawi, a Cabinet committee on HIV/AIDS was formed in 1997 and chaired by the president. In Latvia, a working group was established by NGOs and parliament with the aim of improving AIDS-related legislation.

In 2002, the Bangladesh Parliament Members Support Group (BPMSG) for HIV/AIDS Prevention and Human Trafficking was formed. This organisation works to promote relevant laws and policies and has also been orienting politicians to the issues.

However, many people working on HIV/AIDS issues report that although politicians may make public statements on HIV/AIDS and political structures may exist, political commitment is in fact limited. Concerns expressed include:

- Leaving the issue of HIV/AIDS to the technical bodies in Malawi
- The fact that politicians only talk about HIV/AIDS at special events. For example, in Ethiopia, one respondent commented: *'I do not think that Ethiopian politicians are devoting themselves to the fight against HIV/AIDS. The few top leaders of the country came out on stage and spoke of HIV/AIDS only during special events, for example, in connection with the World AIDS Day, in workshops and in conferences concerning HIV/AIDS. Otherwise, there is a general silence from the side of big officials.'*

Consequently, there is a need to determine what is the evidence of real political commitment and to find ways of measuring this. UNAIDS has endeavoured to do this by developing indicators for monitoring the implementation of the UNGASS Declaration of Commitment. These indicators of national political commitment relate to adoption and implementation of policies and deployment of required financial resources, and both are considered in more detail later in this report.

Respondents were able to identify some indicators of lack of commitment, for example sending a junior civil servant to attend the State–Faith Task Force in Malawi.

Political commitment is not static. It can increase and decrease depending on a range of factors including:

- Individual commitment. For example, in Malawi, there has been a discernible increase in top-level political commitment in recent years. During the time Hastings Banda was president, issues about sex, family planning and HIV/AIDS were not discussed openly. In Ethiopia, greater openness is directly attributed to the leadership of President Girma Woldegiorgis, since he took office in 2002. His role as an active advocate on HIV/AIDS issues was recognised by UNAIDS in 2004
- Influence from civil society and the international donor community. Again, in Malawi, these have both played positive roles in encouraging greater political commitment
- Other political factors, such as instability and conflict. For example, one reason given for the limited political commitment to HIV/AIDS in Haiti has been the issue of political instability and the need for successive governments to focus on priorities other than HIV/AIDS.

Naturally, people working in the field of HIV/AIDS want the issue to be given the highest political priority. However, politicians have to juggle competing priorities and it may not be realistic to expect HIV/AIDS to be given the same priority in all countries. For example, in Latvia, one journalist said *'Politicians don't talk about HIV/AIDS much. There are more important issues like living standards, the salaries of teachers and health staff, corruption and cost of living. Prices went up after joining EU and price of petrol has recently risen.'*

Perhaps it is self-evident that HIV/AIDS will be a higher political priority in some countries than in others, particularly where HIV prevalence among the general population is high, e.g. in Southern Africa. In such countries, illness and death from HIV/AIDS will be a significant issue not only for the health sector but also for the country's economic development. This is clearly not currently the case for countries with low-level epidemics. However, there are significant risks with the argument that countries with low levels of HIV infection in the general population do not need to make it a political priority. These include failing to take appropriate actions at a time when the epidemic can be contained and reversed, and creating the idea that concentrated epidemics are somehow unimportant. This is clearly not the case as concentrated epidemics may affect large numbers of people where vulnerable populations are large, have profound effects on individuals and have a risk of bridging to other populations if the right conditions exist. Perhaps a more appropriate argument is for a different kind of political commitment in countries with low-level and concentrated epidemics. This would mean that rather than focusing on raising public awareness of HIV/AIDS through public events, there should be a stronger commitment to providing services that are known to be effective, if controversial, to the most vulnerable populations. These include condoms for sex workers, MSM and IDUs, and drug substitution therapy and sterile injecting equipment for IDUs. Strong political leadership is required if these services are to be provided for vulnerable populations at sufficient scale to make a real difference.

Financing

As mentioned earlier, the level of national financial resources committed to HIV/AIDS is considered as an indicator of political commitment to the response. So what can be said about this in the seven countries studied?

There are considerable difficulties with tracking spending on HIV/AIDS in a particular country. Although these can be largely overcome by the use of national HIV/AIDS accounts, as recommended by UNAIDS, it does not appear that any of the countries studied were compiling these. Problems encountered include:

- Organisations may not always be clear about whether amounts are those budgeted or expended. Governments, in particular, are often poor at tracking whether amounts budgeted have been spent
- Not all relevant spending may be counted as HIV/AIDS-related. General finances to the health service may not be included, e.g. in Malawi. Health-related human resources are often not included, e.g. in Ethiopia and Haiti, particularly where they work with a wide range of people, not simply those with HIV, e.g. in the Latvia Centre for Infectious Diseases
- Funds come from a wide variety of sources and are poorly coordinated. They are often spent by different organisations which may be reluctant to share financial information with others, e.g. NGOs in Bangladesh. In Latvia, government financing comes from different levels, i.e. central and municipal, and may be poorly coordinated with each other and across the country

- Failure of adequate review of HIV/AIDS spending. For example, in both Latvia and Bangladesh, it was reported that parliament was supposed to oversee government spending on HIV/AIDS but that this was rarely scrutinised rigorously. In some cases, government auditing functions are not considered to be particularly robust.

Most governments have committed some funds to the response to HIV/AIDS although often the amounts have not been large. In Malawi, government resources only comprised 2.4 per cent of the HIV/AIDS budget and in Haiti the figure was around 1 per cent. Ethiopia reportedly had no domestic HIV/AIDS budget. In addition, there were reports that government finances were often released late, that financial systems were unduly complex and that allocation to regions might not be based on need. For example, the north east province of Sri Lanka received almost double the allocation of the western province despite having almost ten times fewer reported PLWHA.

In some cases, governments have systems for allocating funds to civil society organisations, e.g. in Malawi where this is provided through the National AIDS Commission. However, the procedures are described as very complex, particularly for new or less-sophisticated civil society organisations.

In many of the countries, HIV/AIDS seems to be a higher priority for international donors than for national governments

In many of the countries studied, the national response to HIV/AIDS remains largely donor-funded. For example, in Pakistan more than US$47 million was provided to the national response over five years through a donor ‘pool’ including the World Bank, DFID, EU and CIDA. Additional funds were available from other donors, such as the Global Fund for AIDS, Tuberculosis and Malaria (subsequently referred to as the Global Fund) and USAID.

In most of the countries studied, the amount of funds available for HIV/AIDS has increased significantly, e.g. from the Global Fund and, in some cases, the US President’s Emergency Plan for AIDS Relief (PEPFAR). A good example of this is Haiti where the country received a Global Fund grant in January 2003 worth US$67 million and also receives money from PEPFAR, USAID, CIDA and UN agencies.

However, this is not the case for Latvia, particularly since it joined the EU. The decline in donor funding has reportedly affected the NGO sector severely as funds are not currently available either from the government or the EU to run previously donor-funded activities.

Perhaps the biggest problem of donor-led programmes is that agendas may be set by donor organisations and foreign individuals linked to where the finances are. Local/national organisations and individuals may be relatively passive, leaving key issues of driving and leading the response to others.

In addition, the predominant aid instrument used by donors appears to be time-limited projects. This has significant implications for the national HIV/AIDS response which is often characterised by NGOs lurching from one project to another rather than a consistent, coherent and coordinated national response. It also appears that the system favours larger NGOs, e.g. in Bangladesh. There are significant concerns about the sustainability of these responses.

A key problem, particularly with the expanding resources available to countries for HIV/AIDS is their absorptive capacity, that is their ability to receive, use and account for all the funds provided. Examples of problems in this area include failure to use all Global Fund resources in Malawi and ‘sluggish’ implementation of a World Bank loan in Ethiopia. In Bangladesh, slow implementation of a World Bank loan led to the amount being reduced by half. Indeed in Bangladesh, lack of government absorptive capacity is cited as the main barrier to an effective response to HIV/AIDS.

In many countries, the amounts of money available for HIV/AIDS programmes are very substantial. As a result, there are concerns about these fuelling corruption, e.g. where procurement is being conducted, and that, in some cases, people may be only attracted to work in the field because of the money.

As mentioned earlier, UNAIDS has proposed that domestic financial commitment to HIV/AIDS be taken as an indicator of political commitment to the response. While having some validity, it may overlook the relative ability of different governments to finance the response. There is also an argument that the ready availability of donor financing in this field undermines national government financial commitment. The report of the study in Malawi concludes, *'the availability of huge resources tends to curtail the internal national will and hence commitment of individual countries is not all that strong.'*

Although it may be difficult to track spending on HIV/AIDS effectively (see above), some countries do analyse HIV/AIDS budgets. For example, in Malawi, it appears that 34 per cent of the budget is for treatment, care and support, and 18 per cent is for prevention. Less than 2 per cent of the HIV/AIDS budget in Malawi is committed to M&E. In Latvia, government funds are largely spent on HIV tests and provision of medical care and ART for PLWHA. There are concerns in Ethiopia of funds being diverted away from prevention towards ART. In countries with low-level or concentrated epidemics, it appears that funds are not being adequately focused on the most vulnerable populations. For example, in Bangladesh, *'Money are not reaching at the hands of the sex workers, We have to find out how much money are being used for the purpose of the sex workers, for their awareness raising, we do not know whether utilisation of money is taking place as per its allocation.'*

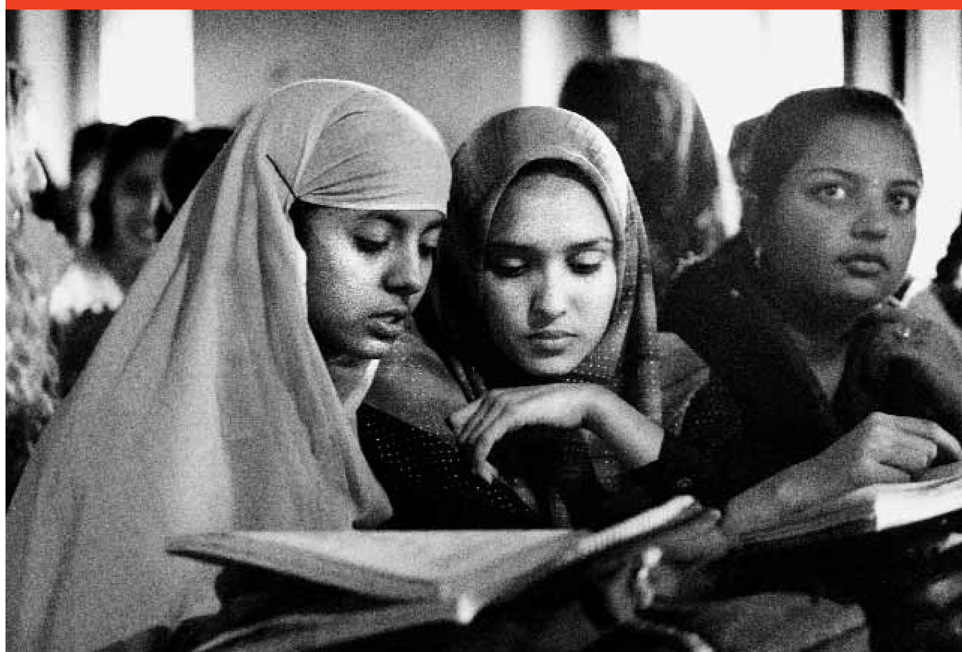
Policies

As mentioned earlier, another indicator proposed by UNAIDS for monitoring national commitment to the response to HIV/AIDS is the adoption and implementation of policy, as measured by a National Composite Policy Index. For example, evidence of political commitment in Sri Lanka was said to include the fact that the government introduced a National Drug Policy and formulated a National Mental Health Policy.

This issue is considered further in this report under the sections on the national responses (page 10) and legislation (page 29).

National responses

3



A multisectoral response to HIV/AIDS could mean an education programme in schools, but the national action frameworks in several of the countries studied focused almost exclusively on the health sector.
TIM DIRVEN | PANOS PICTURES

This section is structured around several elements which may be considered essential for an effective national response, namely a national action framework, a national coordinating authority and a national M&E system.

National action framework

Most countries have some kind of national action framework for HIV/AIDS. Many African countries, e.g. Malawi and Ethiopia, have both a National HIV/AIDS Policy and a National Strategic Plan. In such cases, the policy contains broad guidelines on how the response will be carried out and the strategic plan contains more detail on how these policies are implemented. It is unclear why these elements cannot be combined in one national action framework. In other countries, there is only one document. For example, it is called the National Strategic Plan of Action in Haiti and has a similar title in Bangladesh.

National frameworks have technical strengths and weaknesses

The Panos country studies highlight a wide range of technical strengths within countries' action frameworks, for example:

- The inclusion of surveillance and a focus on vulnerable populations in Pakistan
- A provision for prevention of mother-to-child transmission (PMTCT) in Malawi
- A focus on ARVs and voluntary counselling and testing (VCT) in Haiti.

However, there are also a range of significant gaps in these documents. These include:

- Limited focus on the needs of PLWHA in Sri Lanka
- Omission of OVC in Haiti
- Inadequate focus on the most vulnerable populations in countries with low-level/concentrated epidemics. For example, in Latvia, there is no specific mention of programmes for sex workers or MSM
- Insufficient links to legislation, e.g. in Malawi and Haiti.

While it may be helpful to outline particular technical gaps, there is perhaps a broader, overarching problem with many of the documents, particularly in countries with low-level or concentrated epidemics. In an attempt to consult broadly and to be as comprehensive as possible, the final product ends up being simply a long list of all possible activities with little sense of what is most important. This is summed up in a comment from the Bangladesh study: *'The total document gives a sense of [being a] wish list rather than focusing on specific areas on what to and how to do on priority basis.'*

In general, NGO staff and PLWHA expressed a strong desire to be involved in consultations regarding the development of the national strategic action framework for the response to HIV/AIDS. This happened to varying degrees in different countries. For example, in Pakistan, there were said to have been more than 100 consultations with stakeholders including UNAIDS, civil society organisations and PLWHA. The situation in Malawi was similar (see box below).

Consultations over the National HIV/AIDS Policy in Malawi

NGO staff and PLWHA report that consultations over the proposed National HIV/AIDS Policy in Malawi had been particularly good. The Malawi Network of People Living with HIV/AIDS (MANET) reported that they took an assertive approach to the consultations by insisting that they were fully involved. This resulted in the policy having a chapter dedicated to the needs of PLWHA. In addition, a report commissioned by MANET on stigma and discrimination was incorporated into the policy.

The extent of consultation was less in other countries. For example, in Bangladesh, it was reported that the document was prepared by external consultants and, as a result, it was not *'owned by the people of this country'*. Consultations were seen as being token in nature, for example, conducting them in English when some participants were unable to understand or speak this language. Similar issues were reported in Latvia where the most vulnerable populations, e.g. MSM, sex workers and IDUs were not directly consulted. PLWHA felt that their involvement had been inadequate. For example, *'Officially PLWHA were involved, but they were not so important. It was mostly compiled by specialists.'*

A particular problem documented in this study is that civil society organisations may not have the skills, time or inclination to participate in these consultations, even if they are given the opportunity. For example:

'I got the draft document and did not have the time to give my comments' (Bangladesh)

'Though in some occasions the representatives from PLWHA and other marginalised groups included in the committees but practically they act as passive observer as initiatives are not strong enough for strengthening their capacity for providing meaningful opinion' (Bangladesh)

Most of the frameworks reviewed have involvement of government ministries other than the Ministry of Health and other actors, such as NGOs and PLWHA. For example, in Malawi, the policy provides for each government ministry to have an HIV/AIDS coordinator and to use 2 per cent of their other recurrent transactions budget towards HIV/AIDS activities. However, this is identified as a weak area in Haiti, where the document focuses almost exclusively on the health sector.

A number of other key features of these documents emerged from the Panos country studies:

- They should be based on a situation and response analysis, e.g. in Bangladesh
- They should operate on a renewable time frame, e.g. five years in Malawi
- They should have a dissemination/communication plan, e.g. in Malawi, this involved extensive meetings at national, regional and district level over a six-month period
- They should link to other policies. This does happen in some countries, e.g. Bangladesh but not in others, e.g. Haiti. In Malawi, the policy is linked to other policies on poverty reduction and OVC
- They should have clear and measurable targets. This is a weakness of many plans, e.g. Malawi
- They should contain a clear budget. Again, this is absent from many documents, e.g. Latvia
- They need to contain information as to how things will be done. This can be done in separate documents linked to the policy, e.g. on PMTCT and ART in Malawi
- They are often stronger on paper than in practice. For example, in Ethiopia, key provisions of the policy have yet to be implemented, such as mobilisation and empowerment of civil society organisations, mainstreaming of HIV/AIDS activities in key sector ministries and greater participation of the private sector.

There are many examples from the countries studied of policies being seriously and effectively implemented. For example, in Latvia, key successes of the programme include free provision of ART to PLWHA, improved access to HIV testing and delivery of focused prevention programmes for IDUs, e.g. needle exchange programmes. In Malawi, *'There are a number of achievements in the fight against HIV/AIDS in Malawi. For example the actual mobilisation of resources, especially from the Global Fund, is a milestone for Malawi.'*

However, this is not the case in all countries. For example, in Bangladesh, one respondent reported that the *'government is not much serious for the implementation of the policy. Most of the time their words do not reflect into actions. Strong political commitment is obviously absent. Most of the issues as mentioned in the UNGASS declaration not yet considered as priority issue in terms of concrete action plan.'*

National coordinating authority

In all of the countries studied, there is one or more body in place to coordinate the response to HIV/AIDS. Some of the features of these bodies are summarised here:

- **There may be other coordinating bodies linked to other international/donor agencies**, such as Country Coordinating Mechanisms[5] (CCM) in Malawi and Pakistan, and the UN Theme Group on HIV/AIDS in many countries, including Pakistan
- **Going beyond the health sector** – many of these bodies include representatives from beyond the Ministry of Health. In Malawi and Ethiopia, the National AIDS Commission and the National AIDS Council (respectively) report to the country's president. However, in Ethiopia, the executive body, the National HIV/AIDS Prevention and Control Office, still operates within the Ministry of Health. In many other countries, e.g. Pakistan, Haiti, Bangladesh and Latvia, the coordinating authority is led by/reports to the Ministry of Health

5
Widely seen as Global Fund structures

- **There may be some involvement of NGOs and PLWHA** – however, in some countries, this is seen as largely tokenistic. In some cases, e.g. Latvia, NGO representatives are appointed by government rather than being elected from within the constituency
- **Many of the committees are either non-functional or meet much less often than planned**. Examples include the National Technical Advisory Committee on AIDS in Pakistan and the National AIDS Committee in Sri Lanka
- **Some of the committees are very large** – for example, there are 85 members in Ethiopia and 33 in Sri Lanka[6]
- **Some committees have technical subcommittees for specific tasks** – although this may be a helpful way of dealing with particular issues, especially where the main committee is very large, there are concerns in some countries, e.g. Sri Lanka, that this is just adding another layer of bureaucracy
- **There have been efforts to replicate structures at regional levels** – for example, the establishment of committees in 3,500 *kebeles*[7] in Ethiopia. However, this only covers 16 per cent of the country and it is unclear how well these are working
- **Some committees get diverted from policy issues to operational matters** – e.g. in Sri Lanka
- **Many of these committees have an implementing or executive body** – however, there may be problems with these. For example, in Bangladesh, *'This machinery is working with an ad-hoc basis. It has no stability. People are coming and going. The NASP is very much in need of dynamic leadership, which is missing.'* In Latvia, this executive function is divided into two. The AIDS Prevention Centre has responsibility for epidemiological monitoring and prevention while the Latvian Centre for Infectious Diseases is responsible for care and treatment of PLWHA.

National HIV/AIDS M&E system

National HIV/AIDS M&E systems are still often lacking from policy

The importance of national HIV/AIDS M&E systems is now widely recognised. However, policies are still being developed in some countries that lack them, e.g. Sri Lanka. Others, however, such as Bangladesh, Malawi and Ethiopia, have developed strong and sophisticated descriptions of their M&E systems. Malawi has a particularly comprehensive system covering the requirement of the national policy, major donor programmes and international reporting obligations, e.g. to UNGASS and the Millennium Development Goals. In Ethiopia, the M&E system is accompanied by a detailed operational manual. Despite this, implementation is reported to be weak with very few people aware of the system. This is also the case in Bangladesh where information is only provided for three of ten indicators.

National M&E systems should be an integral part of the national HIV/AIDS policy/strategy and should be constructed around a set of core indicators which measure both progress towards the overall goal (impact/outcome) and the level of services provided. There should be a series of quantifiable targets with appropriate baseline information. M&E systems should also ensure that services are of appropriate quality.

6
Plus a further 13 observers

7
Lowest geographical administration unit in Ethiopia

Reporting systems are often passive, focused on donor requirements and lack feedback to implementers. National bodies may have the responsibility to collect M&E data for the HIV/AIDS response but they often rely on the goodwill of implementers for reports, e.g. in Malawi. This is particularly true for organisations outside the Ministry of Health, where channels of authority do not reach and where no funds are involved. Indeed, in many countries, e.g. Haiti, most reporting is done for donors, not for the national response. Reports often only pass in an 'upward' direction with little feedback to health workers or the general public. For example, in Bangladesh, concerns were expressed that NGOs receive no feedback on M&E data.

Lack of human resources is a major constraint. This may be at national level, e.g. in Pakistan, where there is nobody within the National AIDS Control Programme (NACP) responsible for M&E. In addition, it may be particularly weak at district and community level, e.g. in Malawi. Lack of adequate human resources is identified as the main barrier to effective M&E in Ethiopia. In Bangladesh, the situation is being addressed by using international organisations to conduct M&E, e.g. UNICEF and Save the Children.

HIV surveillance among vulnerable populations in Latvia

Several HIV prevalence studies have been conducted among vulnerable populations in Latvia from 1997 onwards (see Figure 3.1). These show very high rates of HIV infection among IDUs and sex workers. Although some of these studies were intervention-based and may therefore not be representative of all members of a particular vulnerable population, the figures are robust enough to be used as a basis for planning the national response and focusing this even more strongly on the most vulnerable populations.

There is a need to conduct such studies systematically and regularly and to ensure that all relevant vulnerable populations are included in the studies, e.g. MSM and those in prison. A key barrier for doing this is that staff within the AIDS Prevention Centre also have other duties. Additionally, there is a need to produce and analyse the data more rapidly and to strengthen the behavioural elements of these studies.

Future studies should also seek to gather evidence on the size of these vulnerable populations, particularly IDUs and sex workers.

Despite this strong evidence, many respondents in Latvia are unaware of the concentrated nature of the epidemic in the country. When asked who is most vulnerable to HIV in Latvia, they focus on more general groups, such as women and young people rather that on sex workers and IDUs.

There is a pressing need to use this data to focus the response even more strongly on those most vulnerable to infection.

Although, historically, surveillance systems relied too much on passive case reporting, this has largely changed in countries with generalised epidemics and is beginning to change elsewhere. For example, Figure 3.1 and the box above both illustrate progress in this area in Latvia.

Surveillance studies among vulnerable populations are yielding useful biological and behavioural data

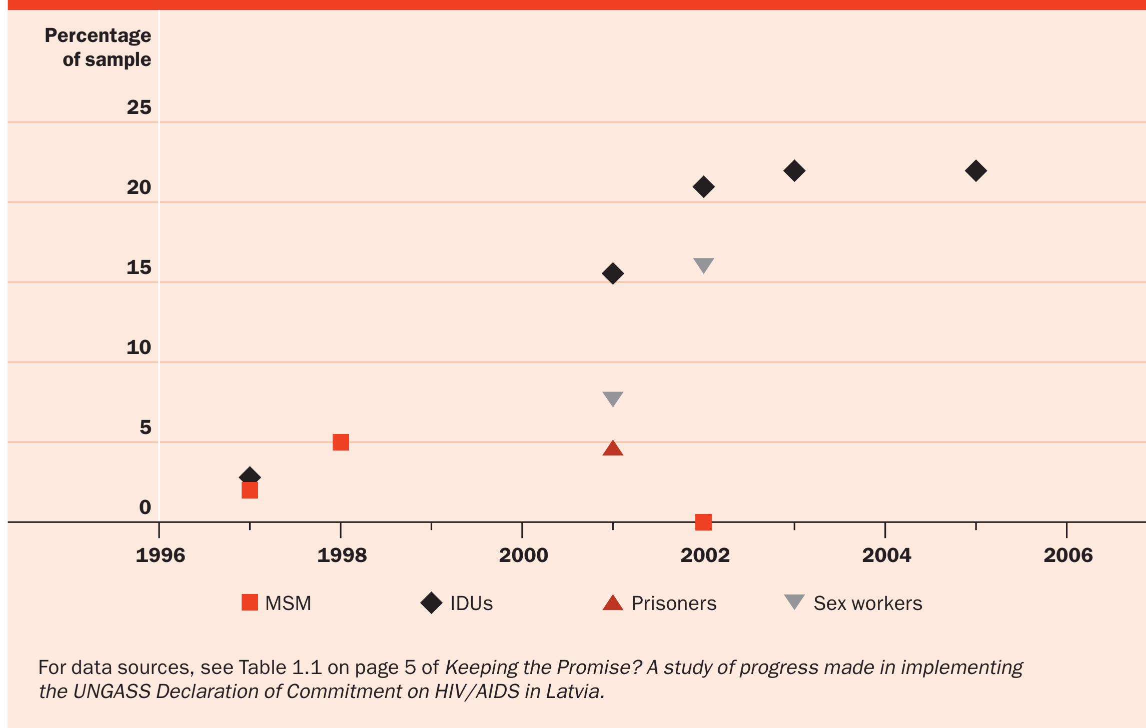
CIDA provided support for surveillance studies among vulnerable populations in Pakistan. These yielded useful behavioural data in addition to information about HIV prevalence among particular vulnerable populations (see page 4). For example, in Lahore:

- 82 per cent of IDUs reported having used a shared needle in the previous week
- 30 per cent of all IDUs bought sex from a woman in the previous month. Of these, 90 per cent did not use a condom.

Areas needing attention in relation to surveillance, particularly in low-level and concentrated epidemics include:

- Sustaining and institutionalising these approaches
- Ensuring data from these studies is synthesised and used as this is not always the case, e.g. Pakistan
- The pressing need to accurately estimate the size of vulnerable populations in a country
- Ensuring that the best available methods are used to obtain the most representative samples.

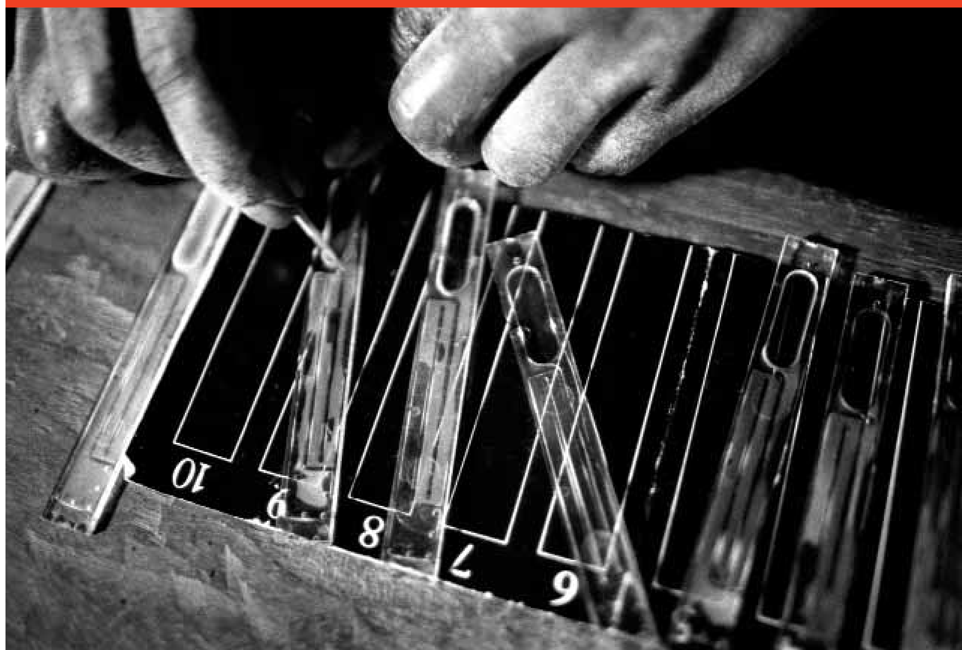
Figure 3.1: HIV prevalence among vulnerable populations in Latvia, 1997–2005



For data sources, see Table 1.1 on page 5 of *Keeping the Promise? A study of progress made in implementing the UNGASS Declaration of Commitment on HIV/AIDS in Latvia.*

Even where data is available, it is not always used to drive programming and appropriate use of scarce resources. For example, it is unclear if the finding that 23 per cent of IDUs in Karachi are HIV positive has led to a major focus on programmes for this population in this city. In Bangladesh, concern was expressed that evidence concerning sex workers is not used to provide more services but instead results in stronger law enforcement.

Service delivery 4



There are concerns that in many of the countries studied, resources and efforts have been diverted to scaling up ART at the expense of other care and support services. In Malawi, for instance, there has been a shortage of home care kits.
PEP BONET | PANOS PICTURES

This section is in four main parts, which focus on prevention, ART, care and support, and services for OVC. Preceding this is a brief review of general barriers to service delivery based on experiences from the Panos Ethiopia study. Although these vary from country to country, there are significant such barriers in each country studied:

- Financial and human resources are limited as is the capacity to manage them, including absorbing and managing financial resources
- Changes in systems, e.g. decentralisation in the health service, are proceeding slowly. There is confusion over accountability and poor flow of information
- There is poor health infrastructure in the country
- Ethiopia is subject to political and social unrest. *'In the past 2 years there was a good sign of political commitment in the country, with top government figures and distinguished personalities coming out in public and speaking about HIV/AIDS and the mass media had also been dedicating a considerable time to HIV/AIDS. However, this year's [2005] political situation, during the election campaign, and its aftermath political unrest appeared to have taken the previous year's galvanised government's attention away from HIV/AIDS. For the most part of this year the mass media has been extremely busy airing political matters…'* [Panos Ethiopia Study]

Prevention

There is a growing recognition internationally that a 'one size fits all' approach to HIV prevention simply does not work. Rather, there is a need to tailor a country's response to the way the epidemic is spreading. Essentially, this means that approaches which are highly appropriate in a country with a generalised epidemic, e.g. in Eastern and Southern Africa, could be highly inappropriate elsewhere.

There are marked similarities between the approaches to prevention in Malawi, Ethiopia and Haiti (see Table 4.1). Activities aim to reach everyone in the population, although there may be some degree of focus on particularly vulnerable or marginalised populations. There has been a marked increase in the level of services in recent years. For example:

- In Malawi, the number of sites offering VCT rose from 70 in 2002 to 146 at the time of the survey. Sites offering PMTCT rose from 7 to 31 during the same period
- In Haiti, the number of sites offering VCT rose from 2 in 2002 to 88 at the time of the survey. Sites offering PMTCT rose from 2 to 77 during the same period
- A similar trend has been seen in Ethiopia, although there are concerns that these facilities are under-used, particularly by the most vulnerable populations.

Table 4.1: Elements of HIV prevention in countries with a generalised sexual epidemic[8]

	Malawi	Haiti	Ethiopia
Information, education, communication (IEC)/Behaviour change communication (BCC)	● [9]	● [10]	● [11]
Blood safety	●	●	●
Use of sterile injection equipment	●	○	○
VCT	●	●	●
Condoms	●	● [12]	●
ART/PMTCT	●	● [13]	●
Treatment and prevention of STIs	○ [14]	●	●

VCT is also being expanded in other countries. For example, in Pakistan, Marie Stopes' Better Tomorrow programme has opened 12 of 16 planned centres.

In a concentrated or low-level epidemic, prevention approaches that would be appropriate for a generalised epidemic are likely to be both ineffective and extremely costly. Conversely, measures focused on the most vulnerable populations are likely to be effective, not only in protecting members of those populations, but also in preventing the epidemic spreading to other groups. However, to be effective, proven measures need to be applied promptly and at a sufficient scale to make a difference.

8
Based on description of objectives and services in the national action framework

9
Described as IEC only

10
Promotion of safer sexual behaviour

11
Mentions both IEC and BCC

12
Through a strong programme of condom social marketing

13
Specifically refers to PMTCT

14
Treated as part of treatment and care

HIV prevention programmes for vulnerable populations in Bangladesh, Pakistan and Latvia

Harm reduction programmes are being implemented by NGOs in **Pakistan**:

- Nai Zindagi works in four cities of Punjab (Lahore, Sargodha, Faisalabad, and Sialkot) and one in Balochistan (Quetta). The programme distributes free syringes to IDUs on the streets
- Another NGO, Amal, works with commercial sex workers in Karachi, providing them with condoms free of charge. A similar programme also operates in Lahore
- Futures Group, supported by DFID, is also involved in harm reduction activities with vulnerable populations through local NGO partners.

In **Bangladesh**, there are very limited drug treatment facilities. The government-run Central Drug Addiction Treatment Centre in Dhaka offers abstinence-based treatment to a maximum of 40 people. Two consortia have been operating needle/syringe exchange programmes through a network of 23 drop-in centres. Two of these, in Dhaka, offer services for female IDUs only. This programme is reaching 7,000 IDUs with a range of services in addition to needle and syringe exchange.

Services are also provided to sex workers: *'We are providing STI service for the sex workers, but we can not ensure adequate STI drugs required for full treatment, as we have budget constraints.'* In addition, sex workers have a wide range of other needs which are currently unmet. These include lack of access to schools for their children and poor amenities in the brothels.

The Bandhu Social Welfare Society provides services to MSM but reports that its funding has been dramatically reduced. As a result, services have closed in Chittagong, Comilla, Rajbari and Dhaka. Their Executive Director reported: *'The closure of the services is likely to have a far reaching effect, for a number of reasons. First, it has had a significant effect in making available services for… MSM. Furthermore, the information so far provided through the National Serological and behavioural surveillance undertaken by the Ministry of Health and Family Welfare Department, Government of Bangladesh would suffer.'*

Perhaps one of the biggest successes of the national response to HIV/AIDS in **Latvia** has been the introduction of harm reduction/needle exchange programmes for IDUs. These are largely credited with the reduction in registration of new HIV infections among IDUs in the country. However, the programme has some limitations: it does not consistently provide condoms to clients, it does not operate in all major cities and towns, services are not available to IDUs in prison and drug substitution therapy is not widely available.

From the evidence presented earlier (pages 4, 14 and 15), we know that Latvia has a concentrated epidemic among IDUs and sex workers, there is a concentrated epidemic among IDUs in Karachi and levels of HIV infection are approaching 5 per cent in IDUs in Bangladesh. Given the speed with which HIV can spread through injecting drug use, the country's location within the region, and close links to other countries, there is a risk of a significant HIV epidemic among IDUs in Sri Lanka.

Consequently, it might be expected that these countries' responses would be highly targeted to these and other vulnerable populations. This is true to some extent for Pakistan, Bangladesh and Latvia (see box on page 18) but is not the case for Sri Lanka, which does not appear to have harm reduction programmes for IDUs and has little focus on the most vulnerable populations for condom distribution activities.

It should be noted that many of the descriptions of these programmes are silent on certain key issues, such as the level of coverage achieved and the availability of other essential services, such as drug substitution therapy. Where there is mention, it is either to note that coverage is very limited[15], e.g. in Pakistan, or that the absence of substitution therapy is a significant gap, e.g. in Haiti. In Bangladesh, there is evidence that coverage levels of services among vulnerable populations are low[16], that services are being reduced due to declining funding and that levels of HIV prevalence among IDUs are known to be increasing. This is strong evidence in favour of focusing limited resources on services for the most vulnerable populations and not being distracted into providing less controversial services for the general population. Indeed, scaling up effective services to the most vulnerable populations is likely to protect the general population much more effectively than seeking to provide prevention services in the same way as would be done in a generalised epidemic. This is also likely to be the case in Pakistan where UNAIDS has raised concerns that the national response is not adequately focused on the most vulnerable populations.

There is little doubt that there needs to be some type of mobilisation of the general public in a country if there is to be an effective response to HIV/AIDS. In the countries studied, the approach followed has been largely the same focusing on increasing awareness of, and knowledge about, HIV/AIDS among all sectors of society, on the basis that this will lead to people making informed choices about adopting safer forms of behaviour. These efforts have been particularly extensive in Ethiopia and have worked through a wide variety of channels including health facilities, mass media, schools, civil society organisations, PLWHA and churches. For example, *'In October 2004, a total of 26 bishops of the Ethiopian Orthodox Church including the Patriarch himself, have engaged themselves in raising public awareness on the prevention and control of HIV/AIDS in different parts of the country. In the campaign the bishops preached about faithfulness, avoidance of stigma and discrimination, as well as care and support to PLWHA. It was believed that the campaign had managed to reach over 500,000 audiences throughout the country and was considered as a major indication of the Church's commitment in the fight against HIV/AIDS in the country.'* Demographic health surveys conducted in the country provide strong evidence that these efforts have resulted in high levels of knowledge about HIV/AIDS.

However, there are some problems with this approach to public mobilisation:

- There is little evidence that increased knowledge leads to changes in behaviour. For example, although surveys in Malawi in 1996 and 2000 showed increasing levels of knowledge about HIV/AIDS, they failed to show any evidence of resulting behaviour change. Indeed, in some cases, behaviour shifted from safer to more risky forms
- In countries with concentrated epidemics, e.g. Pakistan, efforts to raise awareness and knowledge among the general population risk diverting efforts away from more appropriate interventions focused on those who are most vulnerable to HIV
- The focus on public mobilisation, i.e. on HIV awareness and knowledge, risks being too simplistic. For example, in Ethiopia, there was much less public mobilisation around the HIV/AIDS policy and access to ART.

15
A notable exception is services for sex workers in Haiti that are said to be reaching 20,000 out of an estimated total of 32,000, i.e. a coverage of 63 per cent.

16
Based on figures provided of 7,000 IDUs receiving services and 20,000 total IDUs in the country, this would put coverage at only 35 per cent, which is well below the level needed to stop an HIV epidemic spreading through the IDU population.

This is perhaps the key point: not that the general public should not be mobilised but that they should be mobilised in the right way and about the right thing. Mobilisation based on personal risk and focused on awareness, knowledge and behaviour change may well be very appropriate in countries where the epidemic is spreading sexually in the general population. However, such approaches are inappropriate in countries where the epidemic is spreading mostly among particularly vulnerable populations. In such countries, e.g. Latvia, a different approach is required among the general population that is focused on:

- Addressing stigma and discrimination that is experienced by PLWHA and members of vulnerable populations. Unfortunately, there is evidence that some campaigns of public awareness and education about HIV/AIDS end up in building up stigma and discrimination, rather than reducing it. This is particularly the case when using fear-based messages
- Building public support for interventions that make a real difference to members of vulnerable populations and offer a realistic way of protecting the entire population. Currently, the main barrier to effective HIV programming for IDUs in Latvia is public and political opposition to certain interventions, such as needle/syringe exchange and drug substitution. Public mobilisation focused on overcoming these barriers should be a high priority in such settings.

There are a number of sociocultural barriers to effective HIV prevention which are illustrated here by way of quotations:

In Sri Lanka, one interviewee stated: *'A certain private sector employer had installed condom vending machines in the toilets which proved to be popular but they were quickly removed as it was seen by many as encouraging sexual activity rather than as a mode of prevention for HIV/AIDS and other STDs.'*

In Ethiopia, *'Condoms are not yet well accepted by [our] population. Condom use is approved only when it is with a sex worker. For most people carrying condoms in their pockets/wallets or buying it from a shop keeper/pharmacy is less acceptable, and most people feel uncomfortable to do so. If a person seen carrying condoms, the society often portrayed him/her as promiscuous or as someone regularly engages himself in casual sex. This situation is in particular quite grave for women.'*

Also in Ethiopia, *'It is not a simple decision to undergo HIV testing in the face of our culture, religion and limited understanding of AIDS. I do believe that knowing one's HIV status is really good, especially if the result turns out to be negative. The problem comes if the result becomes positive. For our people being HIV positive is considered as a death sentence even if the person is healthy and shows no sign of AIDS. This attitude mainly emerges as a result of the widely spread fear-based message that has been used to describe the disease. In addition, in most cases religious preachers describe HIV/AIDS as a punishment from God and often portrayed the person infected as a sinner. As a result, most people become so hesitant and afraid of undergoing testing for HIV.'*

The report from Latvia states: *'There are some key issues of relevance to prevention efforts… First, concern was expressed that key issues of stigma and discrimination are not being fully addressed and that this is hindering prevention efforts. Secondly, concern was expressed that the national response is too focused on primary prevention, i.e. focused on those not yet infected, rather than on secondary prevention, i.e. focused on those already infected. There is growing evidence that a focus on secondary prevention is more effective in low-level and concentrated epidemics.'*

Antiretroviral therapy

Significant numbers of PLWHA are receiving ART but many more need this treatment. Table 4.2 provides information on the estimated number of PLWHA requiring ART in particular countries. Countries fall into two main groups – those with large numbers of PLWHA requiring treatment (i.e. >25,000) and those with relatively small numbers (i.e. <1,000). Countries with generalised epidemics (Ethiopia, Haiti and Malawi) fall into the first group and countries with concentrated/low-level epidemics (Bangladesh, Latvia and Sri Lanka) fall into the second group. Pakistan falls somewhere between the two groups. As the issues faced differ considerably between the two groups of countries, they will be considered in turn.

Table 4.2: Estimated numbers of PLWHA needing and receiving ART

	Number on treatment in 2004 [17]	Number on treatment at time of this study	Number requiring treatment in 2004
Bangladesh	5	Not known	510
Ethiopia	4,500	25,000	200,000
Haiti	1,370	5,500	40,000
Latvia	87	220	840
Malawi	3,760	32,000	130,000
Pakistan	100	53	10,000
Sri Lanka	25	50	280

- **Countries with more than 25,000 people requiring treatment** have had to decentralise ART provision in an attempt to get ARVs to a very large number of people. For example, Ethiopia now has more than 50 sites providing ART. Both Malawi and Ethiopia now have more than 25,000 people on therapy although the number needing treatment but not receiving it is even larger. Huge challenges need to be overcome in order to reach even more people with treatment. For example, in Malawi, these include distances people have to travel to reach their nearest health facility and the severe problems of providing and taking these medicines in places where people do not have enough food to eat. In Haiti, ART provision was initiated by NGOs (GHESKIO and Partners in Health) but treatment is now being provided in the public sector with plans to further expand this
- **Countries with less than 1,000 people requiring treatment** have provided ARVs in a more centralised manner. For example, in Sri Lanka, free treatment is funded through a World Bank grant and is only available in the STI clinic in Colombo. In Latvia, treatment is being funded by the government and is currently only available through the Centre for Infectious Diseases in Riga. Although some NGOs in Bangladesh are providing ART, this is not currently available through the public sector

It is worth noting that even Latvia, a low-middle-income country that is now part of the EU, has not managed to provide ART to most of the people who need it. Reasons for this include: the high cost and limited budget; some PLWHA do not know their HIV status; one-third of known PLWHA do not register with the Centre for Infectious Diseases; treatment is only available in Riga; and additional support services[18] required by active IDUs are not widely available.

17
From UN epidemiological factsheets

- **Pakistan** has made extremely limited progress in providing ART. Although there are plans to do this in the public sector through five centres of excellence and to have 400 people on ART in the first year, there have been significant delays in procuring drugs. At the time of this study, the only people receiving treatment in Pakistan were either receiving the ARVs from NGOs[19] or were buying them privately.

Being provided with ART can make a huge difference to the individual (see box below) and is highly appreciated by PLWHA. There is strong evidence from Haiti that survival rates for people on ART are comparable to those achieved in richer countries.

All countries studied are facing significant challenges in providing ART to everyone who needs them. For example, in Pakistan, the health system lacks adequate infrastructure and skilled, professional staff. In Haiti, many health care professionals have left the country because of the high level of insecurity and political instability.

Care and support

Care and support is lagging behind treatment

Other treatment services are lagging behind ARV provision. This is particularly the case for treatment of opportunistic infections including tuberculosis (TB). It is widely known that TB particularly affects PLWHA. For example, in Malawi, 77 per cent of all TB patients were found to be HIV positive. Yet, in some countries, e.g. Pakistan, TB and HIV services are poorly coordinated. Also, because of the strong international focus on ARVs, it may be easier to get ARV drugs than treatment for opportunistic infections in some countries, e.g. Haiti. In Ethiopia, it was reported that very few PLWHA were receiving prophylaxis with co-trimoxazole, despite the known effectiveness of this intervention and the much lower cost than providing ARVs.

Experience of ARVs from Ethiopia

'I started the treatment about 9 months ago. At the time when I started the treatment, I had been bed-ridden for about 3 months, and I was almost wasted. I was just counting days for my grave. I had all sort of health problems and was under a long term TB drug. The doctor told me that I needed to take ARV treatment, which was available, free of charge. At the time, I was a bit hesitant because I was afraid of the treatment, of course, for no apparent reason. I was also confused what to do at the time. Sometimes I used to say to myself that I should go to Tsibel (Holy Water). Finally, my home care provider encouraged me to take the treatment – telling me all the positive aspects of the drug, and that was how I started the treatment. The drug did a miracle to me – I just recovered within few months, and the doctor told me that my CD4 increased from 56 to 177 cells in about 6 months. I am now quite a healthy person with the help of the drug.'

18 Particularly substitution therapy

19 Such as CRS

Stigma and discrimination are widespread within health services

There are concerns that in many countries resources and efforts have been diverted to scaling up ART at the expense of other care and support services. For example, in Sri Lanka and Pakistan, care and support for PLWHA is largely provided through NGOs. In both Malawi and Ethiopia, there has been a strong focus on the provision of home-based care (HBC) through faith-based organisations and NGOs. However, in Malawi, this has been hampered by the lack of home care kits and food, so that *'there was a feeling that Government use HBC programmes as dumping grounds for people living with AIDS.'* In Ethiopia, despite the best efforts of NGOs, coverage of services remains low and is largely concentrated on major cities. In Latvia, PLWHA expressed concern about the absence of psychosocial support services. For example, the Centre for Infectious Diseases does not employ social workers even though many of the PLWHA are active IDUs with a wide range of social problems. These examples illustrate clearly the problems which occur when care and support activities are neglected in favour of approaches focused disproportionately on prevention and treatment.

A key concern raised by PLWHA in the countries studied relates to the stigma and discrimination they experience within health services. In Sri Lanka, they explained that this deters people from accessing treatment because they are treated unkindly and unprofessionally. It was also given as a reason why PLWHA sometimes prefer separate or specialised services because they are often treated better there, e.g. at the infectious diseases hospital in Sri Lanka or the Centre for Infectious Diseases in Latvia. In Pakistan, people report that PLWHA often prefer to go to private services because in public hospitals *'there were signs put in front of beds to notify all that they were HIV positive'* and the centres of excellence have big signs saying 'special clinic'. In Ethiopia, stigma is given as a major reason why people do not take HIV tests. Those that do go for services may either be treated differently or denied services.

'One can get treatment but once the doctors know that you are HIV positive, they will tell you that there are no medicines even if they are available.'
Malawi

'I had herpes zoster on my back and went for treatment to a hospital in Daugavpils. The doctor told me that I was a drug user and that I should abstain. I went to Riga instead.'
Latvia

There is a huge need for services for orphans and vulnerable children in many countries

Services for orphans and vulnerable children

In countries with very high HIV prevalence rates among the general population, e.g. Malawi, where many young adults are either sick or die as a result of AIDS, there is a huge need for services for orphans and other children made vulnerable as a result of AIDS. There is general acceptance that these services should be provided to all children considered vulnerable according to criteria established at community level. In such settings, HIV/AIDS is likely to be a major direct or indirect influence on these criteria. This is not necessarily the case in countries with low-level or concentrated HIV/AIDS epidemics, e.g. Bangladesh, Latvia, Pakistan and Sri Lanka. However, this does not mean that these countries do not face challenges related to vulnerable children. Certainly, Bangladesh, Pakistan and Sri Lanka do, but it does mean that HIV/AIDS is unlikely to be a major factor in childhood vulnerability in those settings.

Countries with relatively high levels of HIV prevalence in the general population, but with other significant causes of childhood vulnerability, lie somewhere within this spectrum. Haiti and Ethiopia are both examples of such countries. In these settings, programmes focused on OVC are likely to need to cater for children made vulnerable by many factors other than HIV/AIDS.

Countries with generalised HIV/AIDS epidemics use different policy instruments to address issues affecting OVC. Malawi is the only country of the seven studied that has a specific policy on OVC. Its National Plan of Action for OVC was launched in July 2005 and runs until 2009. Orphans are also mentioned in the National HIV/AIDS Policy which commits the government to assist and empower families and communities caring for orphans, to ensure that orphans have access to education, to support child-headed households and to ensure protection of inherited property etc.

Ethiopia has no specific policy on OVC but does refer to the issue in its national AIDS policy. Many respondents expressed a desire for a specific policy relating to OVC because Ethiopia has a very large number of children orphaned by AIDS – estimated to have been 720,000 by the end of 2003. A survey in 2003 found that roughly one in six children aged under 18 had been orphaned by HIV/AIDS in the country.

Haiti's national strategic plan for HIV/AIDS does not provide for the care of OVC. In addition, there is no specific policy or strategy relating to OVC. This is despite the fact that 1 per cent of children in Haiti are thought to be orphans. The number of vulnerable children could be much higher. An FHI study revealed that more than 900,000 children lived in female-headed households, as fostered children in institutions, with an HIV-positive adult, with HIV themselves, on the street or worked as child labourers. It also concluded that *'These children suffer higher rates of mortality and malnutrition. Fewer are immunised and many must drop out of school. Although some data indicate the pandemic may recently have plateaued, the economic and social problems faced by the children and families affected by HIV/AIDS will not diminish for at least another 15 years.'*

Services for OVC remain patchy, limited in coverage and are largely provided by civil society. Although Malawi has made significant progress in creating an appropriate policy environment for OVC, there are concerns about the limited extent to which this has been implemented in the country. For example, there have been delays in the establishment of the OVC Technical Advisory Support Unit, which in turn has hindered the implementation of some of the activities in the national plan of action.

In Ethiopia, formal services for OVC are largely being offered by civil society organisations, including NGOs and faith-based organisations. A particular feature in Ethiopia is that organisations of PLWHA offer such services, targeted specifically at children orphaned by AIDS. Services offered to OVC include nutritional support, house rent and medical care, hiring nurses to cook food and do cleaning, supplies of educational materials and school uniforms, income-generating activities and arrangement of adoptions. Currently, the numbers of orphans receiving such services is very small. The main barrier reported to be limiting NGOs providing more services is lack of available finance. There are various initiatives addressing this financial lack, including support from PEPFAR which, by 2005, had provided services to 15,100 orphans and vulnerable children in 18 towns.

Services for OVC in Haiti appear to be extremely limited and focused more on institutional services than on community-based support. Only a few hundred children receive these services, whereas the number of OVC in the country is likely to number hundreds of thousands. Institutions currently providing services for children affected by HIV/AIDS include Maison Arc-en-ciel, the Missionary Charity and CRS Haiti. According to an FHI employee, *'"orphans" care is under-evaluated… it is not really visible.'* None of the large agencies is currently carrying out interventions focused on OVC. As a result, activities for OVC are not carried out on a large scale.

Other stakeholders 5

Voluntary counselling and testing blood samples for HIV are two of the prevention services offered by civil society organisations. Indeed, in Bangladesh, this sector carries out the majority of activities within the national response.
GIACOMO PIROZZI | PANOS PICTURES

This section briefly explores the roles of a number of stakeholders other than Ministries of Health and National AIDS Commissions.

Civil society

The most common role played by civil society organisations is as an implementing partner. In 2002, 103 NGOs were providing HIV/AIDS services in Ethiopia and in 2003, 385 were doing the same in Bangladesh. Civil society organisations provide a wide range of services including:

- Focused prevention services for vulnerable populations, such as IDUs and sex workers, e.g. in Pakistan
- Other prevention services, such as VCT
- Care and support services, e.g. CRS in Pakistan, PLWHA networks in Ethiopia.

Indeed, in some countries, e.g. Bangladesh, the majority of activities within the national response are provided by civil society organisations. However, there are a number of challenges in this area. These include: a limited capacity of NGOs in some countries, e.g. Malawi, and overlapping activities and conflict/rivalry between NGOs, e.g. in Bangladesh.

In addition to implementing activities, civil society organisations can play a number of other roles. These include:

- **Advocacy** – for example, for free ARV drugs in Sri Lanka and for the introduction of laws to protect the human rights of PLWHA in Bangladesh. Although much of this advocacy occurs at a national level, there is also a role for community-level/individual advocacy. In Ethiopia, this appears to be a neglected area but two PLWHA associations are involved in this, providing legal and other support to their members
- **Involvement in 'governance' structures for the national response** – the issue of coordinating the national response to HIV/AIDS is covered elsewhere in this report (see Section 3, page 10). Representatives of civil society organisations are increasingly being asked to be involved in these structures. For example, in Latvia, two NGO representatives are members of the National AIDS Steering Committee

- **Monitoring the national response** – this is potentially a key role for civil society but it is not yet well developed in most countries. It is starting in some places, e.g. NAPHAM was involved in the process of generating the 'UNGASS report' for Malawi. However, it is difficult to do in many places because governments may not wish to be held to account in this way. For example, in Latvia the government does not routinely make budget and spending information available to NGOs.

Although there is a tendency to equate civil society organisations with NGOs, this is neither helpful nor accurate. Specific types of civil society organisations involved in the response to HIV/AIDS include:

- **Umbrella bodies of many NGOs** – one example is PNAC in Pakistan, which has 300 members and focuses on capacity building, systems strengthening, action research, dissemination and advocacy. It has a small grants fund for its members called 'Tameer'.[20] Similar organisations exist in other countries, e.g. the National HIV/AIDS Forum of NGOs in Ethiopia which had 131 members in March 2005
- **PLWHA organisations** – such organisations seek to represent the wishes and aspirations of PLWHA. In Ethiopia, roles for these organisations include protecting the rights of their members, educating the public, promoting and participating in the provision of compassionate home-based care services, fighting stigma and discrimination and advocating for responsible behaviour among their members, access to ART, policy formulation and legislation. They often want to be more meaningfully involved in all aspects of the national response. *'We are members of the national AIDS council and other important committees on HIV/AIDS in the country, including the national HIV/AIDS control board and the Global Fund CCM. Participating in these important committees is encouraging and we are very happy with all that. However, I would like to stress the fact that our mere participation in these committees is meaningless unless we are able to influence some of the decisions that concern us. As far as my knowledge goes, PLWHA association did not participate in the development of the national HIV/AIDS policy as well as in the development of the multisectoral strategic framework. Sometimes [we are sent] some draft documents to comment on and participate in workshops but that is just pointless and only a token.'* There may be challenges to develop PLWHA associations and networks in countries with low HIV prevalence, e.g. Bangladesh
- **Faith-based organisations** – in many countries, e.g. Ethiopia, faith-based organisations are involved in the national HIV/AIDS response. This may involve training priests and preachers, promoting abstinence and behaviour changes as methods for prevention and providing care for orphans
- **Community-based organisations** – these are often informal in nature and fall below the 'radar screen' of many donors. Examples include women's associations, youth associations and anti-AIDS clubs. A particular example from Ethiopia is the *Idir* (burial association), a local saving organisation through which people pool their own funds (through monthly contributions) as basic insurance to assist members with the often-high costs of funerals.

Civil society organisations face a number of challenges in responding to HIV/AIDS. These include:

- Uncertain financing which can result in 'lurching' from project to project
- Limited capacity – the capacity that exists may be focused on implementing activities of funded projects and pursuing new funding sources. This may leave little time for consultations
- Inter-organisational competition
- High staff turnover and poor institutional memory.

20 Project in Pakistan run by Interact Worldwide (Urdu word for building)

Media

The main way the media is involved in the response to HIV/AIDS is through coverage of the issues in its normal work. In Malawi, one newspaper has a dedicated page for HIV/AIDS. However, in other countries, e.g. Pakistan and Latvia, HIV/AIDS is not a top priority issue for the media. Nevertheless, in Pakistan coverage is now more regular and in depth, particularly when triggered by special events, such as World AIDS Day. In most cases journalists do not go out actively looking for HIV/AIDS stories but they react to stories that reach them. For this reason, organisations involved in HIV/AIDS issues are developing media strategies, e.g. in Malawi, and run training programmes for journalists e.g. via the Panos fellowship programme.[21]

Other ways in which the media may be utilised in the response to HIV/AIDS are as:

- A vehicle for public/political statements, e.g. in Ethiopia
- An implementing organisation, e.g. for the BCC element of the national programme in Pakistan.

Private sector

In general, the involvement of the for-profit private sector in national responses to HIV/AIDS is limited in the countries studied but may include:

- Promotion of products by pharmaceutical companies
- Acting as a management contractor, e.g. in Pakistan to manage NGO contracts, conduct procurement etc
- As a 'venue' for HIV prevention in high-prevalence settings, e.g. Ethiopia. Most workplace programmes focus on IEC/BCC but some include VCT programmes, e.g. Ethiopian Airlines. One problem identified with workplace programmes is that they exclude the large and significant informal sector.

Other government ministries

One of the key elements of an effective response to HIV/AIDS is that it should be multisectoral, i.e. based in a range of sectors, not just the Ministry of Health. This seems to work better in some countries than others. For example, in Pakistan, there is little involvement of other ministries although some joint initiatives are in an early stage. Ethiopia has a World Bank-funded project entitled Ethiopia Multisectoral HIV/AIDS Project (EMSAP). Many ministries have formed HIV/AIDS task forces and developed work plans. However, neither the Ministry of Health nor the Ministry of Education have managed to mainstream HIV/AIDS into all their work. There is also concern that a growing focus on treatment, in general, and financing from the Global Fund, in particular, has shifted the focus back towards a single-sector approach:

'*While it is assumed that the Global Fund support will have positive impacts on poverty reduction and contribute to sustainable development, there were concerns that the Global Fund support had made HIV/AIDS activities more focused within the MOH. The country's multisectoral approach to HIV/AIDS involves mainstreaming as a basic strategy in HIV/AIDS prevention. Global Fund-supported activities on HIV/AIDS do not appear in alignment with this strategy. Furthermore, since the initiation of the Global Fund grant to Ethiopia, HAPCO which formerly reported directly to the Prime Minister's office and had a special status and mandate to encourage multisectoral approach, has been brought back under the federal MOH. Concerns were also expressed that the roll-out of the ART programme [the lion's share of the Global Fund go to ART roll-out programme] may reinforce this trend towards the "medicalisation" of HIV/AIDS.*'

21
These fellowships are currently available to journalists in Bangladesh, Pakistan and Sri Lanka. More details available from www.panosaids.org/method/mediatraining.htm

International agencies

International agencies also play a variety of roles in supporting national responses to HIV/AIDS. Perhaps the most obvious is providing financial resources but others include:

- Developing policies and codes of practice — e.g. ILO, WHO in Pakistan
- Providing training – e.g. UNICEF in Pakistan
- Acting as a focal point for monitoring, in general, and UNGASS, in particular, i.e. UNAIDS operating in many countries
- Influencing policy and practice – e.g. UNICEF's work with media and religious leaders in Pakistan and multiple donors in Haiti
- Delivering services – e.g. World Food Programme in Ethiopia, UNFPA working with NGOs to provide care and support in Ethiopia.

Supportive environment

6

The media can play a part in promoting more accepting attitudes of people living with HIV/AIDS. A joint radio and television initiative in Haiti between a local NGO, Panos and the government is one example.
ALVARO LEIVA | PANOS PICTURES

Laws

Most of the countries studied (e.g. Bangladesh, Malawi, Haiti, Ethiopia[22]) have no specific laws for HIV/AIDS although some, e.g. Haiti, have considered introducing them. Changes were not made because of the ongoing instability in the country. Malawi's National AIDS Commission has commissioned a legislative review related to HIV/AIDS.

Pakistan made HIV/AIDS a notifiable disease in 1998 and is currently considering introducing legislation on the mandatory testing of blood products. Bangladesh already has legislation on blood safety. In addition, there are:

- Some general laws relevant to HIV/AIDS – for example, in Malawi, the constitution and Employment Act 2000
- Some problematic laws – for example, criminalisation of homosexuality in Sri Lanka, Bangladesh and Malawi, and requirement for mandatory HIV testing of foreigners who stay in Sri Lanka for more than one year
- Some missing laws – such as rights of PLWHA, provisions for consent, confidentiality and workplace legislation in Sri Lanka
- Some laws that are not enforced – for example, in Haiti, it is reported that *'people's rights are usually ignored, unrecognised or not respected'*. In Latvia, although legislation exists to prevent people from being dismissed from work for being homosexual or for being HIV positive, most respondents reported that it would not be enforced
- Unhelpful applications of laws – such as arresting IDUs for possessing syringes or arresting sex workers for having condoms. Many HIV/AIDS programmes report problematic relationships with the police. For example, in Latvia, one female street worker reported, *'Yesterday, I was with another street worker and 4 clients and we were stopped by the police not far from here. The clients wanted to get needles and to talk about rehabilitation. When they saw the police, they ran off. The male police officers searched me and my colleague. It happens often and it is useless to say that I should not be searched by a male police officer… The police know that we are street workers but they treat us as criminals.'*

There are a number of initiatives to try to improve HIV/AIDS-related legislation, such as a UNAIDS-initiated parliamentary forum in Pakistan.

22
Although Ethiopia's National AIDS Policy has certain provisions on medical confidentiality, employment protection etc

Stigma and discrimination

People living with HIV/AIDS and members of vulnerable populations continue to face stigma and discrimination

PLWHA and members of vulnerable populations continue to face stigma and discrimination. Examples of this in the countries studied include:

- Segregation in hospitals in Pakistan
- Hostile attitudes from health workers in Haiti
- In Latvia, PLWHA may find it difficult to find a surgeon willing to conduct elective surgery for them. Pregnant HIV-positive women may find it difficult to find a supportive doctor to provide maternity care
- Denial of medical treatment in Malawi
- Refusal of food aid in Malawi
- Denial of NGO loans in Malawi.

Of particular concern is the consistent reporting of significant stigma and discrimination within the health sector, e.g. in Haiti, Latvia, Pakistan and Sri Lanka.

Some examples of stigma and discrimination experienced by individuals include:

'When my husband was diagnosed as HIV positive, the doctor told us that we can not eat together'
Woman in Bangladesh

'We are not comfortable to discuss our health problems with the doctors, as, soon they understand our status, their attitudes immediately get changed'
Sex worker in Bangladesh

'… in practice we see significant discriminatory behaviour of the medical personnel while serving the PLWHA'
Professor in Bangladesh

'I would not be willing to disclose my positive status. It will ruin my reputation'
PLWHA in Bangladesh

'Health workers are very hostile to PLWHA in some health centres… A PLWHA does not have the right to drop a cotton ball in the basket after blood sampling'
PLWHA in Haiti

'In general, people see male homosexuals as "rubbish"'
Respondent in Latvia

'You are just wasting my time as you are already dead'
Reportedly said to PLWHA in Malawi

There are many causes of stigma and discrimination. These include misconceptions, fear and the provision of wrong information. Stigmatising attitudes may be shared unconsciously in the media, e.g. in Bangladesh (see below). There is little doubt that much of the stigma associated with HIV relates to the way it spreads and cultural norms concerning sex, and, where relevant, injecting drugs. For example, people may experience stigma and discrimination if they have sex with someone of the same sex in Haiti and Latvia, if they inject drugs in Latvia or if they engage in 'illicit' sex in Pakistan. In many situations, PLWHA experience 'double stigma' related both to their HIV-positive status and to the vulnerable population to which they belong. In Latvia, stigma and discrimination were reported to be particularly severe outside Riga.

Stigma and discrimination hinder prevention efforts and initiatives to expand ART

Stigma and discrimination have significant practical implications. People may be unwilling to take an HIV test (e.g. in Bangladesh, Malawi and Pakistan) or reveal their HIV status to others (e.g. in Pakistan and Sri Lanka). As a result, demand for services, such as VCT may be lower than expected. In Malawi and other countries, people may travel to other geographical areas for HIV testing and other HIV-related services in order to avoid their HIV status being known in their home area. In some countries, e.g. Haiti, people may seek private medical treatment in an attempt to maintain their anonymity.

Stigma and discrimination may be affecting take-up of ART (e.g. in Ethiopia), both directly because people are unwilling to attend openly for treatment, and indirectly, because people are reluctant to have an HIV test in the first place.

All these factors contribute to the spread of the epidemic and to driving it underground in some places, e.g. Haiti. Stigmatising attitudes towards certain populations, e.g. MSM, contribute significantly to such populations being concealed and 'hard to reach'.

Effective interventions to tackle stigma and discrimination are limited

There are reports from three countries[23] that levels of stigma and discrimination are declining. It may be helpful to briefly review measures that can be effective in tackling stigma and discrimination and the extent to which they have been introduced in particular countries. These include:

- **Supportive legal and policy framework** – in many countries, respondents reported that the legal and policy framework was inadequate to address stigma and discrimination experienced by PLWHA and members of vulnerable populations, e.g. Ethiopia and Haiti. In Latvia, the national AIDS strategy does not contain specific provisions to address stigma and discrimination and in Sri Lanka, respondents reported that a policy on addressing stigma and discrimination was needed
- **Research** – focused on identifying issues relating to stigma and discrimination experienced by PLWHA, e.g. as conducted by MANET in Malawi
- **Specific public awareness campaigns focused on promoting more positive attitudes and behaviours towards PLWHA and members of vulnerable populations** – as mentioned earlier, respondents expressed concern that awareness work with the general public is largely focused on raising awareness and general knowledge of HIV/AIDS and has extremely limited focus on tackling stigmatising attitudes and discriminatory behaviours, e.g. in Bangladesh. In some countries, e.g. Sri Lanka, education campaigns are being conducted based on the assumption that increasing knowledge about HIV/AIDS will result in a reduction in stigma and discrimination. Unfortunately, there is strong evidence, e.g. from Ethiopia, that such an approach to HIV/AIDS education can result in increased stigma and discrimination, particularly where messages are based on fear
- **The role of the media** – unfortunately there are many examples of where the mass media has contributed unwittingly to increasing the stigma and discrimination experienced by PLWHA and members of vulnerable populations. For example, in Bangladesh journalists defended things they had written on the basis that they were 'true' despite the fact that they promoted stigmatising attitudes and discriminatory actions. Nevertheless, there are examples from some countries of situations where the media has been used to promote more accepting attitudes and more equitable actions. These include:

– The radio soap opera in Ethiopia called 'Journey Through Life' which tackled the issue of stigma and discrimination associated with HIV/AIDS among many other issues

– A joint initiative in Haiti by CECOSIDA, Panos and the government to use radio and television to reduce stigma and discrimination experienced by PLWHA

23
All with generalised epidemics – Malawi, Ethiopia and Haiti

- **Role models** – a number of different groups can act as positive role models and thus lead to a reduction in stigma and discrimination. This can be done both by what they say and particularly by what they do. Examples include:
  – National role models including political leaders, government officials, well-known personalities and religious leaders
  – Community role models including home care providers and health workers
- **PLWHA acting as the 'face' of HIV/AIDS and lobbying for their rights** – where PLWHA are able to be open about their status, they are able to both lobby with decision-makers for their rights and also to act as a public face of HIV, showing that the disease affects real people of a wide range of ages, sex and background. However, the first people to live openly as HIV positive in a hostile environment may face particularly extreme stigma and discrimination.

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