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Missing the message? provides an overview of these issues, and suggests how the problems of HIV Communication can begin to be addressed through work with policymakers, civil society and the media.

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Missing the Message?
20 years of learning from HIV/AIDS

The Panos Institute exists to stimulate debate on global development issues. Panos works from offices in 11 countries. Since 1986 the Panos AIDS Programme has provided in-depth information on the social and economic causes and consequences of the 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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This document critically re-examines the successes and failures of the last 20 years of the global response to AIDS. Through analysis of the historical response and today’s policy and donor context, we argue that it is time for nothing less than a fundamental reappraisal of HIV communication strategies.

Current international interest, funding and mobilisation for AIDS create a unique opportunity to build an effective response to the crisis. But few of the lessons of the past are contributing to current approaches. Past successes have been characterised not only by strong national leadership but also by open public debate. Ownership and participation are vital. What works is when the energy, anger and mobilisation of civil society have been at the forefront of our responses. Too little in today’s response to AIDS fosters these dynamics.

With AIDS becoming increasingly mainstream within policy discourse, Northern policy agendas can often overshadow local needs and priorities. Funding is crucial, and still far from adequate. Yet the amounts now being made available may lead to conflict, inefficiency or rushed decision-making unless these allocations are more strategic and consultative.

In addition, donors increasingly have to prove impact, showing how money distributed is used to optimum effect. This results in an overemphasis on simple indicators and short-term results, at the cost of long-term change. Yet AIDS is a long-term and complex problem requiring approaches which will not all be simple to measure.

On the basis of our analysis of what has worked in the past we present a number of principles to guide us on how communication can be best used in the response to AIDS. Approaches should move from putting out messages to fostering an environment where the voices of those most affected by the pandemic can be heard. This shift from message to voice marks a fundamental and radical shift in the response to AIDS. While HIV/AIDS information and key health messages remain crucial, it is important to look beyond these messages – no matter how empowering and context-sensitive they might be – and help to develop environments where vibrant and internally derived dialogue can flourish.

To move this thinking forward we outline three areas which urgently require more emphasis, thought and attention. Within each of these areas we highlight the challenges in fostering the debate and social mobilisation that have characterised past successful responses. At policy level, particularly amongst donors, these include longer-term engagement, greater inclusiveness in consultation, more participatory decision-making and greater transparency. Within the media, these include the beginnings of a critical reappraisal of media training, and also the importance of working on media structure, legislation and regulation. And within civil society, there is a need to increase emphasis on advocacy, and on more sophisticated relations with the media.

Little of this will be simple to implement. However, in the midst of another annual world AIDS campaign, and with the threat of the response becoming increasingly “business as usual”, we add our voices to those calling for a critical examination of today’s fight against the pandemic.
Introduction
hopes and fears

There has never been a time when fighting AIDS has been such a global policy concern. Determined, courageous, insistent advocacy by people from the highest level of government right through to those at the frontline of civil society, has succeeded in making the response to this pandemic a top priority within international development. Even as international media and policy agendas have been dominated by the events surrounding September 11th and the conflict in Iraq, AIDS has still retained its position among the international community’s most urgent priorities.

There has also never been a time when so much energy has been translated into so little hope: so little hope that the pandemic will be contained in the medium term, and so much concern that the strategies being pursued are not those which will have the greatest effect in the long term. There is a real fear that if the current mobilisation against HIV/AIDS fails, then humanity will, as it has done in the past, turn its back on one of the gravest public health crises in human history. For this reason, it matters that the resources, energies and strategies being devoted to tackling the pandemic are not only sustained, but are also focused on strategies that are successful over the long term.

Beyond a few notable successes, the record of tackling this pandemic has been poor. Over 22 million people have died in 20 years, and more than 42 million people are infected with a virus which was unknown in 1980.¹ The vast majority of these people live in poverty. And yet the virus is fragile and cannot survive outside the human body for more than a few minutes. Simple prevention methods provide good protection against its most common form of transmission. It is difficult to reach any other conclusion than that our failure to confront and contain this pandemic is one of history’s most spectacular demonstrations of humanity’s failings.

¹ UNAIDS (December 2002)
AIDS Epidemic Update, Geneva.
Panos published its first dossier on HIV/AIDS in 1986. In that document, *AIDS and the Third World*, we warned that HIV/AIDS threatened to become the most serious public health issue facing developing countries; that Africa would be most heavily affected, and that if a major international response was not mobilised against the pandemic, up to a quarter of adults would become infected in some countries. We also argued that the epidemic was both a cause and a consequence of underdevelopment. Any strategy required to tackle it would need to be rooted in an understanding that the spread of HIV/AIDS is inextricably linked to issues of gender inequality, discrimination, poverty and marginalisation.

Seventeen years later, this document is designed to assess some of the key historical lessons that should have been learned from the development of the pandemic to date, and to assess whether current strategies are reflecting these lessons. We argue that much of what was known almost two decades ago about the dynamics of this pandemic has not been applied in tackling it, and much that has been learned during the last 20 years is still not being sufficiently reflected in anti-AIDS strategies.

Our central conclusion is that the most effective responses to HIV/AIDS are those which emerge from within societies; and they tend to be long-term, complex and difficult to evaluate. These are precisely the strategies which donors, despite their best intentions, find most difficult to support. We argue that some strategies, particularly those which involve large sums of money being spent rapidly in the expectation of rapid results, are often ineffective and may even sometimes do more harm than good.

We believe that the characteristics of this pandemic, caused by a virus that takes up to 10 years between infection and symptoms to appear, and inextricably bound up with complex issues of sex and sexuality, prejudice and discrimination, poverty and inequality, demands a long-term strategy. Very few experts and commentators on this pandemic expect it to be contained within the next 10 years, and most argue that any real impact will take at least two decades to achieve. No widely available vaccine or cure is expected to be developed within at least a decade.

The international community has committed itself through its Millennium Development Goals to have “halted by 2015 and begun to reverse the spread of HIV/AIDS”. Panos argues that, despite many positive and courageous steps by initiatives such as the Global Fund to Fight AIDS, TB and Malaria (GFATM), funding structures and policies are poorly positioned to support the kind of long-term, cross-sectoral, difficult-to-evaluate and locally driven initiatives that constitute the most appropriate responses to HIV/AIDS. There are several initiatives by large organisations to respond to these concerns, but unless these become more widespread and more deep seated, then the international response to HIV/AIDS will not be sufficient to meet the Millennium Development Goals. In some instances, international responses can even undermine rather than strengthen the kind of social and national responses required.
Since the title “AIDS” was first given to the immune problems and diseases attacking young American men two decades ago, over 22 million people around the world have died of AIDS-related illnesses.\(^2\) Although much has been achieved in this time, the sheer number of people dying from AIDS – more than three million in 2002 alone – urges a rethink in the response to the pandemic.\(^3\)

The vast majority of deaths have been in less wealthy countries, particularly in sub-Saharan Africa, which has accounted for 84 per cent of the world’s global AIDS deaths since the beginning of the epidemic.\(^4\) Although these poorer countries bear the brunt of the pandemic, decisions on how to respond to AIDS are predominantly taken by the donor community in the North – or by national government bodies which have little contact with those most affected by the virus. The fact that there are now over 42 million\(^5\) people living with HIV/AIDS, is a testimony to a failure by national and international agencies to combat the epidemic.

There have, however, been major success stories in the fight against AIDS which hold important lessons for the current and future response to the pandemic. One set of characteristics runs like a thread through nearly all of them: ownership, participation and a politicised civil society. What works best are interventions taking place within the context of societies which have strong social networks and strong internal communication structures.\(^6\) While major externally conceived education efforts, condom promotion, social-marketing and other mass media campaigns have often played an important role, and have generally attracted the most funding in HIV/AIDS efforts, they too have succeeded best when they operate in a context and environment that has been shaped within a country or society.

While this document seeks to draw some general lessons from how the pandemic has been fought to date, its principal focus is on identifying and developing more effective communication strategies to contain HIV. While major breakthroughs, both in types and costs of treatment, are transforming the response to AIDS, and giving new hope to HIV-positive people, communication continues to hold the key to containing HIV transmission and coping with the effects of the pandemic.
Building on principles that have been grouped together under the banner of “Communication for Social Change” (see section 3), we believe that participation, ownership and accountability should be central to the response to the epidemic. Approaches need to go beyond the expert-led public health campaigns and the generally inadequate processes of participation and consultation that currently typify how HIV/AIDS is being tackled. Too many information, education and communication campaigns designed to change sexual behaviour have been short-term, non-empowering, top-down and lacking in long-term impact. While these campaigns are extremely valuable, they do little to foster the kinds of long-term, multidimensional strategies that we believe to be also necessary to tackle this epidemic.

What worked where?

For many years now, the international HIV/AIDS community has pointed to a small number of countries – principally Uganda, Thailand, Senegal and, to some extent, Brazil – as success stories; countries that have successfully contained, or made substantial impacts in slowing, the spread of HIV. For the same amount of time, HIV/AIDS strategies have largely ignored the major lessons of these countries and the reasons for their success.

While these examples are arguably the clearest success stories from the last 20 years, some caution is needed when drawing lessons from these experiences. Many argue that successes in Uganda (which provides a particular focus of this document) have been exaggerated and even mythologised. None of the other examples are straightforward to interpret either. Senegal had strict social control over sexuality, partly because of its largely Muslim population. In Thailand, sexual behaviour may have recently taken a turn for the worse. In Brazil, although medicines for AIDS are now available, because of stigma and lack of testing, the majority of those living with HIV remain undiagnosed and untreated. In some settings, success may be tied to particular contexts and lessons may not be transferable.

In others, notably in Cuba, an effective AIDS response was achieved through a mix that included a number of the communication lessons highlighted below, but through a system of state control and denial of rights that are unacceptable in most countries and which have unpredictable long-term effects. These words of caution aside, the failure of the global response to HIV/AIDS to date compels analysis of what has worked, and demands identification of what can be transferred.

National political leadership: critical, but insufficient

There is a virtually universal consensus that political leadership is the single most important element of any effective HIV/AIDS strategy, and has been critical in most of the outstanding success stories of the pandemic.

It is the story of Uganda which perhaps provides the best clues to what constitutes an effective strategy against HIV/AIDS, not least because it is the only African country which has suffered a catastrophic epidemic but has both reversed and survived it. It is also a country which has been subject to the most analysis, interpretation and argument.

Uganda started to report declining seroprevalence rates in 1992, and although there is some dispute as to just how strong this decline is, almost all experts agree that the country represents one of the few clear examples where HIV has at least begun to be contained. Nearly all this analysis cites political leadership as being the most critical element in shaping and implementing the response to AIDS, particularly from President Yoweri Museveni. Repeatedly, the speed, determination and consistency of purpose from government is identified as a critical factor in mobilising the HIV/AIDS response. Museveni's personal understanding and commitment to fighting the pandemic, backed up by equally committed and determined ministers, such as his health minister Dr Ruhakana Rugunda in the 1980s, was fundamental to Uganda's success.

Political leadership is also often cited for Senegal's success. In terms of speediness of response, Senegal could be said to take the lead. Although among the world's poorest countries, it has benefited from relative political stability since independence in 1960. The country's Socialist Party's tenet of public education aided rapid public awareness of HIV/AIDS. Before the emergence of HIV, the country was advanced in terms of legislation for commercial sex work, and in the quality control of its blood banks. Thanks to strong political commitment and to speedy action, Senegal did not allow the epidemic to break out of the initial high-risk groups. Instead, the government acted immediately to establish a national AIDS control programme when the first six AIDS cases were identified in 1986. It has maintained one of the lowest HIV-prevalence levels in sub-Saharan Africa, with a 0.5 per cent prevalence measured at the end of 2001. Its neighbours Gambia, Guinea-Bissau, Mali and Sierra Leone, have comparative rates of 1.6 per cent, 2.8 per cent, 1.7 per cent and 7.0 per cent respectively.

Thailand provides another much-lauded example of political leadership. In 1991, 143,000 Thais became infected with HIV. A decade later, only a fifth of this number became infected. Although Thailand took longer to respond than many other countries, once catalysed, a comprehensive AIDS response flourished in a very short space of time. At this time, known as the “Prague Spring” for AIDS in Thailand, the Prime Minister took the chair of the National AIDS Committee, and the AIDS budget rocketed from $2.5m in 1991 to $48m in 1992 – with most of this money being locally sourced rather than from external donors.

Similarly strong leadership was demonstrated in Brazil. Here, one of the most notable successes has been to pass a law providing anti-retroviral drugs to everyone testing positive for HIV. This helped halve the number of yearly AIDS deaths over the course of the late 1990s. Despite pressure by the US, the Brazilian government had the leadership and vision to order national pharmaceutical companies to manufacture generic versions of the expensive AIDS drugs, and now provides these drugs to more than 125,000 people. This is, though, still a minority of those infected, and most Brazilian People Living with HIV/AIDS (PLWHA) remain unaware of their HIV status.

Political leadership in all these instances was important in mobilising a broad-based national response to the epidemic. It helped create a motivating and enabling environment in which many other non-governmental actors could take urgent action on the pandemic. It provided a framework, together with the efforts of civil society, in which other external actors could offer the necessary resources, knowledge and skills.
But in many countries at greatest risk, the most typical responses to date from political leaders have been denial that there is a problem, insistence that cultural values will protect their society, fear that any response will harm the image of the country, and official blame – either on other countries or on specific elements within their own societies. Many millions of people have become infected with HIV in countries such as Zimbabwe, South Africa and many others as political leaders have stood by and watched, sometimes undermining rather than supporting civil society and international efforts to combat the epidemic.

Given the severity of the pandemic and the record of governments to date in responding to it, the entire global response cannot be predicated on a massive change of heart and improvement in response by all governments. Furthermore, some countries have demonstrated real political commitment with little effect on AIDS. In Malawi for example, where President Bakili Muluzi made HIV/AIDS an important political priority almost immediately on discovering the gravity of the epidemic in his country in 1994, the country has continued to suffer an acute and growing epidemic, with adult prevalence currently standing at 15 per cent.19

Because political leadership is just one ingredient in the response, and is sometimes beyond successful intervention, there is a need to learn from other constituents of successful responses. The lessons from Uganda – and other countries – suggest that other important factors were at work that made the strategy successful, and many of these have broader lessons for the international efforts to fight HIV/AIDS.

The civil society response

Another characteristic of all these countries is a strong, vibrant civil society. In Uganda, while Museveni and other Ugandan policymakers were playing courageous leadership roles, a powerful civil society was emerging, within a climate that encouraged non-governmental organisations (NGOs) to tackle social problems and issues. Organisations like TASO (The AIDS Support Organisation of Uganda) had already been formed before significant international interest in the issue had emerged. Established in 1987 by a small group of Ugandans affected by AIDS and determined to respond publicly, the movement was, together with the media, encouraged by a more open political system. As a consequence, when funding did become available, there were viable organisations already in existence which could be supported. Although new organisations and funding have proliferated since, there was a bedrock of principles and ownership that had already been established within the country at an early stage. This contrasted sharply with other countries where organisations emerged only when funding became available.

In Senegal also, right from the start, the national response accommodated the involvement of all levels of society, with commentators noting the importance of the partnerships between women's groups, faith-based organisations, government agencies and private sector bodies.20 Senegalese religious organisations, and particularly powerful, traditional Christian and Muslim religious leaders who are prominent members of society, played a major role in launching religious-based HIV/AIDS campaigns and in treating PLWHA. As early as 1989, Jamra, a conservative Islamic organisation, joined the government in HIV/AIDS campaigns.21 This was followed by the publication of *Guide Islam et SIDA*, which not only spread basic facts about HIV/AIDS, but also highlighted how adhering to Islamic teachings could help prevent the disease.22 Although Jamra did not support the use of condoms or condone premarital sex, it was vital in discussions on AIDS between the government and religious organisations.
In Thailand, civil society responses, aided by relatively progressive government support, played a key role. In 1991, for instance, there was only one Thai support group for people living with HIV. By 2001 there were 400. These groups helped campaign for greater access to treatment, destigmatisation, and the provision of support and vocational training for PLWHAs.23 Most of the money paying for this work was locally sourced. Mechai Viravadiya – “Mr Condom”, as he became known in Thailand – started as a civil society activist and became an extremely effective government minister in Thailand, helping to champion AIDS as a critical issue in the early 1990s. In the 1980s, before momentum within the political response to HIV/AIDS had been built, Mechai was an outspoken critic of government impotence in fighting AIDS. He called the Thai Cabinet to account, and demanded that the Prime Minister become Chair of the National AIDS Commission.

The first engagement of Brazilian civil society came from gay groups in São Paulo, Rio de Janeiro and Bahia in 1982. While the country was still under the rule of a right-wing military dictator, these groups revealed that discrimination was a huge obstacle to combating the disease and that it was vital to inform the whole population on prevention measures. They launched information campaigns, promoted public debate and pressed the government to take appropriate measures to fight the epidemic. Following this, the first civil society organisation entirely dedicated to HIV/AIDS was formed in São Paulo in 1985. In 1986, after the end of the military dictatorship, Brazil's national AIDS programme was established. Thereafter, an increasing number of civil society groups helped reinforce the government's response to the pandemic. Today there are many hundred such organisations. Success in Brazil occurred in an environment where the community was already politicised – following the overthrow of a military regime in the early 1980s – and where several reformist activists were recruited into the government response to the epidemic.

Where civil society is pre-politicised in this way, there seems to be a ready platform for action. For example, just after the fall of the military regime, activists, including gays, sex workers and members of the women's rights movement, took to the streets, demanding that their health needs should be addressed. Just prior to the law making anti-retrovirals available, people living with HIV took the government to court on the basis of their “Rights to Life”.

This pattern of civil society sparking political interest has been echoed around the world. In Lusaka, Zambia, commentators have attributed the dramatic fall in infection rates amongst young women – halved since 1993 – to the proliferation of civil society initiatives.24 In South Africa, India, China and many other countries either already in the midst of, or anticipating, severe epidemics, civil society has been a crucial catalyst and resource for the response.

**Politicking the epidemic**

If the role of civil society has been critical in confronting HIV/AIDS where political leadership has been strong, it has been indispensable in the very many more countries where it has been weak. Globally and historically, leadership on HIV/AIDS issues has more often come from the bottom of society than it has from the top. Civil society movements on HIV/AIDS have not only been critical in raising awareness of HIV/AIDS issues in terms of health and sexual behaviours, but they have also been the main instigators in politicising it.

Nowhere is this more true than in South Africa, where AIDS workers for many years struggled to raise the profile of the issue in the midst of both political and public indifference. One of the greatest catalysts for engaging the public was not an educational campaign but a political one, the Treatment Access Campaign (TAC). TAC represents South Africa’s civil society’s answer to the problems it faces in bringing treatment to its citizens. It was started in 1998 by South African AIDS activists, many of whom had a long history of struggle against the apartheid government, and is chaired by the charismatic Zachie Achmat, who is HIV-positive himself. Since then, this dynamic organisation has become the leading voice in criticising both the South African government and the international trade restrictions that affect the import of pharmaceuticals.

One of the key accomplishments of TAC was to take AIDS out of a purely health orientated discourse and to politicise it, helping to put AIDS on the South African agenda, and to put South African failures in leadership on the international media agenda.\(^{25}\) TAC has publicly taken on a group of key scientists and decision-makers who questioned the link between HIV and AIDS. It also challenged the Ministry of Health, obtaining court orders instructing public health services to provide HIV testing and treatment to pregnant women. TAC leaned on the South African government to issue compulsory licences allowing the purchase and manufacture of generic drugs for the treatment of HIV/AIDS. It has implemented a defiance campaign, importing WHO-approved fluconazole from Thailand and worked with Médecins Sans Frontières (MSF) to import generic anti-retrovirals from Brazil. At the time this document went to press, the government had finally committed to supplying treatment to people living with HIV/AIDS, but had yet to start providing the treatments.

Much of the success of TAC comes from the fact that the campaign represents the voice of a community at the epicentre of the AIDS crisis. As Nathan Geffen from TAC put it, “TAC’s members are primarily poor people, many living with HIV. The movement has managed to do this by operating in poor communities … TAC establishes branches in all communities that we can. These branches meet regularly, elect representatives to our structures and are the backbone of the organisation. Without this community mobilisation, we would not have had any success and would not have become a social movement.”\(^{26}\) The urgency and authenticity of this voice, together with snowballing levels of community participation, have given TAC a credibility that no externally derived project could hope to achieve. TAC works closely with the media – having good regular contact with journalists of key South African papers, and using publicity stunts to gain greater media pressure on key issues.

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26 Own conversation.
The Treatment Access Campaign echoes earlier highly effective mobilisations against HIV. These emerged from civil society organisations exhibiting the same mix of vision, anger and political will. In the early 1980s the gay community in the North, while suffering extremely heavy losses to AIDS, was effective in educating itself, in campaigning for recognition, destigmatising HIV/AIDS and securing resources for treatments. It did this in the face of widespread political indifference and inaction from government authorities. The politics and networks of gay rights provided a ready platform and capacity for fighting HIV/AIDS, and the epidemic served to consolidate and provide a unifying series of concerns for the movement. The gay activists were vocal, highly political and engaged with policy and public discourse on AIDS and sexuality at almost every level. The response took place in a context of relative wealth, good education, and a host of other cultural factors, far removed from the reality of AIDS in developing countries. It was unfortunate, and largely for these reasons, that the massive political response to AIDS mobilised by the gay movement in the North was not for many years echoed by a similarly effective political response in the South. Perhaps one of the great missed opportunities in the history of the epidemic was, despite important attempts by many activists, the inability of this movement in the North to mobilise political will on behalf of those with HIV/AIDS in developing countries.

There is a growing scepticism of some current civil society responses. Some complain of the emergence of “briefcase” NGOs, who exist to seek and receive funding available for HIV/AIDS. Even in Uganda, a new slang word – FatAIDS – has emerged to describe organisations which allegedly are too motivated by the funds available, and not enough by the issue itself.

**The importance of open dialogue**

It is self-evident that containing a virus that is principally transmitted (in Africa at least) through sexual intercourse requires widespread changes in sexual behaviour. It is much less evident that the principal strategies that have been used to bring about such behaviour change – formulating and communicating messages to persuade people to be abstinent, faithful or use a condom – have been successful. Changes in behaviour have happened when information is passed between people, rather than being directed at them.

A key lesson relates to the extent to which people talk about HIV/AIDS. In Uganda, for example, the degree to which people communicated with each other has been cited as one of the most important factors in containing the epidemic. According to the United States Agency for International Development (USAID): “The most important determinant of the reduction in HIV incidence in Uganda appears to be a decrease in multiple sexual partnerships and networks … such behaviour changes in Uganda appear related to more open personal communication networks for acquiring AIDS knowledge, which may more effectively personalize risk and result in greater actual behaviour change. Comparing Demographic and Health Survey data with Kenya, Zambia and Malawi, Ugandans are relatively more likely to receive AIDS information through friendship and other personal networks than through mass media or other sources, and are significantly more likely to know of a friend or relatives with AIDS. Social communication elements, as suggested by these kinds of indicators, may be necessary to bridge the motivational gap between AIDS prevention activities and behaviour change sufficient to affect HIV incidence.”

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A similar claim comes from Josef Decosas, who worked for the Canadian International Development Agency (CIDA). “The ‘success’ of Uganda is due to shift in the risk profile. It was not, or at least not solely, brought about by a number of individual prevention programmes. In fact, some of these programmes, as for instance condom promotion, did very poorly in comparison to other countries. The shift was brought about by a societal change at the community level. This change, which is best described as an increase in HIV competence, is characterised by an increase in social cohesion. Similar changes can be found in many communities all over Africa, and they can be promoted through appropriate public policy and programming. Strengthening community organisations to create greater community cohesiveness is one approach to shifting the risk profile of a population.”

Others have defined social cohesion as when “People have a sense that they are engaged in a common enterprise; they believe they are facing shared challenges; they are members of the same community; and they are hopeful.”

Uganda stood out as a country where issues of sex and sexuality could be discussed relatively openly, a situation brought about by many cultural and societal factors, some of which may have been unique to the country. Across Uganda the open media environment, the leadership of Museveni and the broad community-owned response, all led to a climate where sex and sexuality could be discussed increasingly openly, and where taboos around discussion of condom use could be broken down. It also created a climate where vigorous public debate could focus on these issues, and on more fundamental issues of sexual equality, the quality of health systems and inequalities in society. It is increasingly accepted that sexual behaviour change is heavily dependent on fundamental social change of this kind. Uganda provided an environment where dialogue and debate could generate such change. The openness that resulted also led to a climate of increased tolerance where people living with HIV/AIDS could make their voices heard (particularly through courageous and dynamic individuals such as Philly Lutaaya, the HIV-positive Ugandan singer who campaigned vigorously and publicly on these issues).

Within the response of the gay community in the North the same kinds of characteristics of social cohesion and open dialogue were crucial. Within the Californian gay community, researchers have shown clear links between peer contact and the personalisation of risk, associated with safer behaviour. People were openly talking about sex and HIV/AIDS, and were working together to promote prevention and care. Crucially, according to Decosas, when the internally derived emphasis on peer networks and support was scaled up, and exported to other parts of the world, the emphasis on social cohesion was lost: “what was ignored in the transfer of knowledge was the analysis of scale. Peer support among the gay community in the USA worked well without national coordination or National AIDS Programmes. But when international agencies imported the idea to Africa, they did in their habitual format. What we ended up with were billboards on the road to the international airport.”

The importance of the media

A vibrant, professional, free and independent media was key to the Ugandan success and played an important role in each of the other AIDS success stories mentioned here. In Uganda, under new-found political freedoms in the mid-1980s, enabled again by an effective political leadership, a strong, credible and highly professional media began to emerge. Reporting on HIV/AIDS was intensive, sometimes sensational and inaccurate, but often pioneering. The Ugandan media created initiatives such as Capital Doctor on a new private radio station, Capital FM, and Straight Talk, a youth magazine with wide readership through the largest circulation, government-owned paper of the time, New Vision. These initiatives have been sustained and built on by others.

It is often argued that mass media campaigns are not effective in directly changing individual sexual behaviour, and this is sometimes true. However, the media is critical in stimulating public debate and dialogue, and in challenging the kind of long-established social norms that prevent more widespread changes in behaviour. In Uganda, these initiatives were crucial in opening up and reflecting in the public sphere discussions that challenged previously conservative attitudes to sex and sexuality. Media coverage particularly challenged conventional attitudes to the position of women in Ugandan society and sparked discussion and dialogue in society.

Condoms – the only priority?

One factor that appears not to have been critical for Uganda was major condom social marketing and mass media education initiatives. The report from USAID, which has been one of the world’s greatest supporters of condom social marketing, argues that “Condom promotion was not an especially dominant element in Uganda’s earlier response to AIDS … it seems unlikely that such levels of condom use could have played a major role in HIV reduction at the national level.”

Globally, more money has been spent on social marketing of condoms than possibly any other prevention strategy. The availability and affordability of condoms to those at risk of HIV/AIDS makes them a demonstrably useful and important component of any AIDS strategy (they played a core role in Thailand, for example). However, the simplicity and rapid delivery of such strategies have tended, Panos believes, to lead donors to place them at the centre of their HIV/AIDS prevention efforts, rather than as one component. Increasingly, the evidence from Uganda and other countries strongly suggests that condom distribution and social marketing initiatives have been supported more because it is easy to do so than through a clear analysis of the kinds of (often more difficult to support) strategies that create lasting impact.

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More recently, initial liberalisation of radio has led to an explosion of commercial FM radio stations, with some of the most popular programming being talk shows, phone-ins and discussion programmes. Ten years ago there were two major radio stations in Uganda. Today there are almost 80.\textsuperscript{33} There is arguably no other country in Africa where an issue such as HIV/AIDS has had the opportunity to be – and has been – so intensively discussed in all its complexity. The USAID Uganda study suggests interpersonal communication networks were critical in changing behaviour. The kind of intensive public debate that typified the Ugandan environment may have been amplified and made more effective by the newly liberalised media. In this respect, those designing HIV/AIDS prevention strategies should examine how the media environments of the worst-affected countries can facilitate this kind of public debate and dialogue.

In Thailand the media also played a key role, both for information dissemination and as a catalyst for political change. The precursor to the Thai political leadership described above was the communication environment, including a relatively free and plural media, by South-East Asian standards, that helped Mechai and other civil society actors promote the AIDS agenda, and become such a powerful force for political advocacy. Although the Thai broadcast sector was still closely allied to government, the press provided the scope for public debate and the expression of a number of divergent views, including those of the AIDS activists. And once HIV/AIDS climbed up the list of political priorities, the press media accommodated a massive media campaign. The intensity of the Thai\textsuperscript{34} fight against AIDS was such that each day, in the early 1990s, there were 73 hours of AIDS messages on the radio, and two hours of TV coverage.

As in Uganda and Thailand, the Senegalese government was prompt to introduce education and awareness campaigns, with the mass media at the forefront. Mass media campaigns included information dissemination but also aimed to stimulate broad and often difficult public debate. This included broadcasts of HIV/AIDS-based discussions by religious leaders and health officials on radio and television, and the production and dissemination of brochures, pamphlets and billboards.\textsuperscript{35}

While this document argues for an emphasis on communication that goes beyond particular health messages and addresses the channels and capacities for locally derived dialogue, debate and ultimately ownership of the response, some communication models have been extremely effective at combining both approaches.

\textsuperscript{33} Own correspondence.


Competing with the best soap-operas in commercial television, *Soul City* in South Africa has run to five series since it began in 1994 and currently reaches over 16 million people. *Soul City* tapped into the pulse of the community through extensive qualitative research. And *Soul City* combined its mass media approach with social mobilisation and advocacy components to extend the project’s impact. Particularly since the late 1990s, it connected to other organisations that support more participatory communication. The *Soul City* 4 series in 1999 included a focus on youth sexuality, HIV/AIDS and violence against women.

According to Shereen Usdin, head of the *Soul City 4* campaign: “We formed a partnership with the National Network for Violence Against Women, which works both in rural and urban settings. We have developed the material together with grassroots organisations and embarked on a mobilisation campaign together. All research and actual material for the Soul City Series 4 went through consultation with the stakeholders.”

Shereen Usdin believes that the success of the *Soul City 4* campaign as an ‘edutainment’ project is down to the participatory input generated by this collaboration with community-based organisations: “The involvement of a massive grassroots coalition greatly extended the impact of our show.”

As part of its advocacy work, the *Soul City 4* campaign targeted the Department of Social Security, the Department for Development and the Department of Justice, all of which deal with the issue of violence against women. These main policy actors were lobbied quite intensively. In this way the edutainment messages could be subject to dialogue and debate – and could form the inspiration for a range of localised policy and advocacy work. In a practical sense, as one commentator puts it, “Soul City can concentrate on creating a professional media product because it is well linked with other partners who are placed for doing work with the community.”

The work of the National Network of Women Against Violence (NNWAV), in partnership with *Soul City*, successfully mobilised communities and individuals to work against violence against women, as well as advocating policy and legislative changes to eradicate this type of violence. The campaign set up a 24-hour toll-free helpline, provided advocacy skills training to the NNWAV, conducted community-level activities and advocated at a policy level for legislative changes – a process helped by *Soul City’s* popular standing and authoritative public profile. Advocacy and media activity on violence against women created a groundswell of public opinion, as recalled by those involved in initiating the bill:

“There were pressures … from occasions where people held marches and stuff like that.” SA Police Services

“…there were a lot of newspaper reports about the Domestic Violence Act … the concerns, it’s long overdue.” Department of Justice

“You get phone calls every single day from people wanting to know what the hell is going on, why are you delaying the process?” SA Police Services
Local expertise

In Uganda, another key factor was an established indigenous research community, and a small number of energetic, committed senior Ugandan doctors who publicly highlighted HIV/AIDS as a major public health challenge. Concerns were being raised by doctors even before Museveni came to power. In 1984, Dr David Serwadda, then a medical officer at the Uganda Cancer Institute in Mulago National Referral Hospital in Kampala, alerted his seniors, including Dr Sam Okware, the chief epidemiologist, that symptoms of an increasingly common disease appeared to be the same as those affecting AIDS patients in the United States. This small medical community, including a few expatriate doctors, became a key authority on HIV/AIDS both for the Ugandan government and the public, as well as the international community. Ugandans could turn to their own experts for analysis and explanations, and take pride in the fact that these experts, as well as their government, were increasingly informing the international response to the pandemic.

In Senegal, university-based researchers started work on AIDS as early as 1983 and had already begun collaborative research work with foreign academics. In 1984–5, the leading researcher, Dr Mboup, together with his team of academics and scientists, discovered a strand of HIV different from that in Europe. The resultant international recognition of Dr Mboup played a major role when the doctor, accompanied by several senior academics and scientists, visited President Diouf to convince him that an HIV/AIDS campaign was needed. It was Senegal’s lead role in research on HIV/AIDS that helped build political consensus behind the campaign and to solidify the coalition of support. The President’s acceptance of local and international scientific advice, coupled with funding from USAID, facilitated the establishment of Comité National Pluridisciplinaire de Prévention du VIH/SIDA (CNPS). From 1986 to 2001, the CNPS was lead by Dr Mboup, in close collaboration with governmental agencies and ministries, and members of the civil society – religious leaders, academics and PLWHA.
Other key factors for success

Because Uganda and the other examples mentioned above are so often held up as models for success in the fight against HIV/AIDS, it is worth outlining some of the other factors emphasised by commentators.

1 There is a need to integrate a multi-sectoral approach combining medical and socio-economic dimensions.\(^{38}\)

2 Rigorous surveillance and an understanding of the local patterns of an epidemic underlie successful interventions, with broader health interventions such as blood screening and STI control being important.

3 Political leadership needs to be based on medical and scientific evidence. Fighting AIDS should be a test of political legitimacy, with every leader expressing his commitment.\(^{39}\) Action must then follow these words.

4 National leadership and coordination should not suffocate decentralised planning and implementation.\(^{40}\)

5 Interventions need to target women and youth, and address stigma and discrimination. They should be rooted within an understanding of the dynamics of inequality that underlie the pandemic.

6 Faith based organisations play a key role in many effective responses, and partnerships with these organisations can be highly productive.

7 The media has a key role in setting policy agendas. Where AIDS is put on the policy agenda, this has often been preceded by strong media engagement with the issues.

8 Role-modelling has played an important role, for example Philly Lutaaya in Uganda (see above).

9 A gendered approach to HIV/AIDS is important. This includes taking into account how gender roles create vulnerability in women, and reinforce risk patterns in men's behaviour.

\(^{38}\) Ibid.


Some of the lessons we draw from the analysis above have started to be acknowledged and documented over recent years. In particular, there appears to be growing consensus that focusing on the risky behaviours of individuals is insufficient when not taking into account the social determinants and deep-seated inequalities driving the epidemic. In this section we describe some of the main initiatives confronting these issues and then look at why so little current HIV/AIDS programming and funding engages with these fundamental lessons.

In 2001, a major meeting of donor, multilateral and international communication organisations and practitioners came together in Nicaragua for the Communication for Development Roundtable. This is a biannual event which in 2001 focused on AIDS communication, and was organised in part by the Panos Institute (with UNFPA, UNESCO and the Rockefeller Foundation). The conclusion of the meeting was summarised in its final declaration:

“Existing HIV/AIDS communication strategies have proved inadequate in containing and mitigating the effects of the epidemic. For example, they have often:

– treated people as objects of change rather than the agents of their own change;
– focused exclusively on a few individual behaviours rather than also addressing social norms, policies, culture and supportive environments;
– conveyed information from technical experts rather than sensitively placing accurate information into dialogue and debate;
– tried to persuade people to do something, rather than negotiate the best way forward in a partnership process.

Progress in slowing the epidemic will require a multi-sectoral response and use of communication to tackle the behaviours related to the spread of the epidemic and to address its causes (inequality, prejudice, poverty, social and political exclusion, discrimination, particularly against women).”

41

Panos/UNFPA (2001)
Two further processes of strategic thinking have had a particular impact in moving these discussions forward. First, a major re-examination of communications programming by UNAIDS, which involved consultations in all major regions of the world and which culminated in the publication of *A Communications Framework for HIV/AIDS: A New Direction* in late 1999.42 Second, the work of the Rockefeller Foundation Communication for Social Change Network and the allied work of the Communication Initiative (www.comminit.com), which bring together the shared experience of major multilateral and bilateral agencies and other organisations with international experience, such as the Center for Communication Programs (CCP) at Johns Hopkins University, US, and the Institute for Health and Development Communication, Soul City, South Africa.

**UNAIDS – A Communications Framework for HIV/AIDS: A New Direction**

This UNAIDS framework was published in December 1999 following an intensive process of detailed consultations in Asia, Africa, Latin America and the Caribbean. Its conclusions were that:

“Based on a review of the literature and of experiences in the field, most current theories and models [of HIV communication programming] did not provide an adequate foundation on which to develop communications interventions for HIV/AIDS in the regions…”

Participants at five consultative workshops (two global and three regional) noted the inadequacy and limitations of current theories and the models derived from them. Chief among the weaknesses identified were that:

- **The simple, linear relationship between individual knowledge and action, which underpinned many earlier interventions, does not take into account the variation among the political, socio-economic and cultural contexts that prevail in the regions.**

- **External decision-making processes that cater to rigid, narrowly focused and short-term interests tend to overlook the benefits of long-term, internally derived, broad-based solutions.**

- **There is an assumption that decisions about HIV/AIDS prevention are based on rational, volitional thinking with no regard for more true-to-life emotional responses to engaging in sexual behaviour.**

- **There is an assumption that creating awareness through media campaigns will necessarily lead to behaviour change.**

- **There is an assumption that a simple strategy designed to trigger a once-in-a-lifetime behaviour, such as immunisation, would be adequate for changing and maintaining complex, life-long behaviours, such as consistent condom use.**

- **There is a nearly exclusive focus on condom promotion to the exclusion of the need to address the importance and centrality of social contexts, including government policy, socio-economic status, culture, gender relations and spirituality.**

- **Approaches based on traditional family planning and population programme strategies tend to target HIV/AIDS prevention to women, so that women, rather than men, are encouraged to initiate the use of condoms.**
“The major finding was that five domains of context are virtually universal factors in communications for HIV/AIDS preventative health behaviour – government policy, socio-economic status, culture, gender relations, and spirituality. These interrelated domains formed the basis of a new framework that could be used as a flexible guide in the development of HIV/AIDS communications interventions. Individual health behaviour is recognised as a component of this set of domains, rather than the primary focus of health behaviour change.

Most HIV/AIDS communications programmes have been aimed at achieving individual-based changes in sexual and social behaviour. While aspects of this approach are desirable and should be maintained, evidence from research and practice in many countries shows that existing approaches generally have major limitations; thus, a broader focus is needed. Moreover, there is considerable inter-regional variation in the context of HIV/AIDS. Many of the theories, models and frameworks currently in use in the regions do not adequately address the unique needs of HIV/AIDS communications...

The challenge of this new direction is to ensure a redirection of intervention programmes to recognise that individual behaviours are shaped and influenced by factors and domains within a broader contextual focus.”

The Rockefeller Foundation Communication for Social Change Network: behaviour change depends on social change

The findings of the UNAIDS report strongly echoed the work and conclusions of the network facilitated by the Rockefeller Foundation which brings together experts and people working in communication, ranging from grassroots and community-based NGOs through to international NGOs and major multilateral and bilateral organisations. The Foundation's conclusions are also that while mass education campaigns aimed at changing individual behaviour play an essential role in AIDS prevention, they are highly unlikely to be successful or sustainable unless they are accompanied by deep-rooted social changes. These will only result from internally driven change processes, including informed and inclusive public debate.

The principles and approach associated with Communication for Social Change have been summarised as follows:

- Sustainability of social change is more likely if the individuals and communities most affected own the process and content of communication.
- Communication for social change should be empowering, horizontal (versus top-down), give a voice to the previously unheard members of the community, and be biased towards local content and ownership.
- Communities should be the agents of their own change.
- Emphasis should shift from persuasion and the transmission of information from outside technical experts to dialogue, debate and negotiation on issues that resonate with members of the community.
- Emphasis on outcomes should go beyond individual behaviour to social norms, policies, culture and the supporting environment.
**The need to measure**

Because one of the key obstacles to mainstreaming approaches based on the communication principles outlined above revolves around donors’ need to prove impact, the next step is to develop ways to monitor and evaluate these kinds of programmes.

The first challenge in this process is to articulate what the new generation of locally owned, locally driven, social change approaches actually looks like. Mapping the processes here is problematic, because each situation will necessarily bring about a unique response, involving unique groupings of individuals and organisations, and communicating to or from a unique constellation of actors.

One way of tackling this very real problem is to focus on what is actually meant by “communication for social change” and then examine this more narrowly defined process in terms of its constituent parts. This is precisely what has been done in a recent paper that came out as part of the Communication for Social Change Working Paper Series, developed by the Johns Hopkins University Center for Communication Programs for the Rockefeller Foundation.44

Although the paper touches upon issues such as the role of leadership, the role of the media, participation, accountability and ownership within the response to HIV, it does so from a perspective which is above all concerned with the interplay of collective action and community dialogue.

It explains that there are a number of steps that typify community dialogue and collective action. The advantage of having this process articulated in terms of a sequence of events and actions is that it is then possible to measure the degree to which those events or actions have been completed. So one can look at issues such as the selection of leaders, levels of participation, the ways in which conflict is resolved – to name but a few. And because there are a number of clearly defined steps and processes, the map of progress for a social change initiative actually becomes very detailed – certainly generating a clear enough picture to argue the case for continuing funding for a project, or for the scaling up of a venture.

This topography of the change process may cause unease in a number of commentators, purely because it describes a process in a language and framework which is alien to the community where the process will take place. So this categorisation of the process may not be appropriate for all settings, and perhaps the image of a “facilitator” or “change agent” explaining the process to a bemused audience of stakeholders brings with it associations of other top-down approaches. Ultimately this process or framework has been conceived in the North for application in the South, and although supremely flexible, still outlines a process of change which may not reflect the approaches or perspectives of those most affected by the issue.

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While there remains no cure for AIDS and no vaccine, and effective treatments remain widely unavailable to the poor, the greatest weapon in humanity’s armoury to contain this pandemic remains humanity’s most unique characteristic – communication. An overwhelming conclusion from the experience of Uganda and other successful countries is that the extent to which societies have healthy communication environments, the extent to which people talk to each other within communities and between communities, are critical factors for their success. The next section of this report examines some of the major challenges that face those working in today’s response to AIDS in learning from these lessons.

Arguably, the paper finds the best balance to what are essentially two opposing sets of needs and perspectives. On the one hand the donors need to prove impact and sell their ideas to those holding the purse strings, and on the other the communities most affected need to be given sufficient input and creative agency. In this sense there will always be a tension between the need for a coherent framework required by a donor, and the need to allow local communities this creative space – and where one draws the line will depend on the policy climate of the day as much as any more theoretical consideration. There is still an urgent need for more research and the development of models and indicators for measuring communication programming. This is a point we highlight later in the document.
The policy and donor environment

At an international level, HIV/AIDS has been firmly back on the agenda of Northern governments since the G8 group of nations discussed the issue at the Okinawa summit in July 2000. World leaders committed themselves in the UN Millennium Development Declaration in 2000 to have “halted by 2015 and begun to reverse the spread of HIV/AIDS”. These Millennium Development Goals have become the benchmark against which the international community, including the G8, measures its commitment to developing countries. That meeting, combined with many other initiatives, brought about the process that led to the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001 – the first time that such a session had been called to discuss a health issue – and the establishment of the Global Fund to Fight AIDS, TB and Malaria (GFATM) in the same year. At the summit of the Organisation of African Unity in Abuja, Nigeria in 2001, African leaders also committed themselves to the fight against HIV. In 2002 the G8 reaffirmed their commitment to fighting HIV/AIDS in their Africa Action Plan. This action plan was published as a response to the New Partnership for Africa Development (NEPAD). The action plan lists “Improving Health and Confronting HIV/AIDS” as one of its eight main areas of concern. However, the action plan’s objective for an increase in development assistance by $12 billion per year by 2006 has not yet materialised, and frustration with the inaction following these commitments is growing.

Money matters

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates global spending on HIV/AIDS in middle and low income countries during 2003 to be $4.7 billion, a clear increase from the estimates for 2002 which range from $1.5 billion to $2.8 billion. This is still only half of what the UN estimates is needed. While some countries are decreasing their overall development budget, the proportion of money spent on HIV/AIDS is generally going up. Figure 1 shows the level of donor spending of the 21 largest bilateral donors from 1996 to 2000 and of the US from 1996 to 2002. The US, for example, has seen a six-fold increase in overseas AIDS assistance since 1995, and UK AIDS spending is estimated to have increased from £38 million in 1997/98 to £207 million in 2001/02.

45 The United Nations has formed a number of projects around the Millennium Development Goals to measure and support their implementation. For more information, indicators and a full list of the goals and targets see http://www.un.org/


48 Ibid.

49 Own correspondence.
Money is desperately needed to fight this epidemic but funding remains insufficient. The costs of treatment for people with AIDS, although falling rapidly, massively outstrip the health budgets of most developing countries. Médecins Sans Frontières estimates that the cost of treatment has dropped to under $300 per person per year. However, for a country like Uganda, with a health budget of $107 million\textsuperscript{50} in 2002/03 – or just $4.28 per capita – this is still far too expensive for the country to provide treatment for all who need it. If more sustained political and financial commitment had been given when the scale of the epidemic became clear in the 1980s, much of this cost, as well as the massive suffering of millions of people, could have been avoided. Money matters, but what matters most is the context in which money is spent, who defines the priorities for funding, and how effective HIV/AIDS programmes are in the long term.

The current response to HIV/AIDS is often defined as a “global emergency”, raising expectations among donors and Northern publics, as well as among many people most affected by the epidemic, that it can be tackled rapidly. An emergency – a situation that by definition arises suddenly and can be expected to be alleviated by immediate, intensive and urgent action – suggests that providing large sums of money will solve the problem over a short timescale. But HIV/AIDS is a long-term, chronic crisis requiring a sustained, long-term commitment.

Such long-term impact is only likely to be generated if funding is provided for and within strategies that are clearly owned by the societies most affected. Some commentators go so far as to argue that constraints imposed as a consequence of external funding could be an active hindrance to effective strategies against HIV/AIDS. A *Washington Times* report on USAID’s response goes further than this, noting the words of Dr Norman Hearst, an epidemiologist at the University of California: “I’ve had people tell me that the only reason they were successful is that there were no European or American experts there.” This seems an overstatement. Expertise, and the sharing of expertise, is crucial. It is when outside experts start setting the total agenda for the response that real problems arise. In the same article, Elaine Murphy, a global health specialist at George Washington University, argues that “Uganda mobilised as if it were World War III – they did this without donor money on their own.”

**Bilateral aid and saying ‘no’ to funds**

Bilateral aid, given by one country to another, accounts for a large proportion of money coming into the AIDS sector. In 1999, 67 per cent of all aid was given bilaterally. This type of aid has a profound impact on what gets funded and what does not. Allocation of these funds is decided through processes which are essentially political. Governments’ overseas funding is generally subject to discussion in the relevant parliamentary sub-committee and then voted on in the overall budget. In most cases, the spending levels also reflect an administration’s political preference and interdepartmental power relations. Once the money is voted on, it is dispersed to government agencies, NGOs and multilateral organisations, who in turn might disperse it further. In all these highly political processes there is limited scope for input from countries in the South.

**Holding to account**

There are a number of ways in which the progress of policymakers in working on AIDS can be measured. These serve as tools and references which civil society organisations can use to great effect when evaluating the progress of their national leaders.

**The UNGASS Declaration of Commitment on HIV/AIDS:** UNAIDS has developed a set of national, regional and international indicators, monitoring the implementation of the policies stipulated in UNGASS at every level. UNAIDS published its first progress report in September 2003, representing the most concise monitoring tool for the UNGASS commitments.

**The Abuja Declaration:** In April 2001, African heads of state pledged “To place the fight against HIV/AIDS at the forefront and as the highest priority issue in our respective national development plans.” While the declaration mentions a number of specific areas of HIV/AIDS on which they aim to concentrate, such as vaccine research, African leaders committed themselves to spending 15 per cent of their respective national budgets on health. This benchmark provides an overall indicator of a government’s commitment to fighting the pandemic. Once again, few African governments have met this commitment.
Missing the Message? 20 years of learning from HIV/AIDS

The Millennium Development Goals (MDGs): All UN member states adopted the Millennium Declaration, which sets out eight goals to be achieved by 2015. The goals relate to a set of targets and each target has a number of indicators to monitor progress. Goal six aims to “Combat HIV/AIDS, malaria, and other diseases”. In relation to HIV, goal seven aims to “Have halted by 2015 and begun to reverse the spread of HIV/AIDS”. The three indicators monitoring progress towards this target are HIV prevalence among young pregnant women, rates of condom use, and number of children orphaned by HIV/AIDS.\(^\text{56}\)

The AIDS Program Effort Index (API): Developed by the Policy Project funded by USAID, the API is designed to measure the impact of national policy environments on prevention, treatment and care of HIV/AIDS, as well as on the state's ability to mitigate the impact of HIV/AIDS. This methodology quizzes key figures from a range of backgrounds, and includes components measuring political support and organisational structure.\(^\text{57}\) While the API scores are not linked to a specific goal, they are used for monitoring many of the benchmarks described above, including the UNGASS Declaration of Commitment.

The Global Fund to Fight AIDS, TB and Malaria (GFATM): The GFATM is continuously scrutinised by a number of governmental and non-governmental organisations. Key points of interest are: the amounts of cash being made available to the Fund; the applications being refused and accepted by the Fund; and the processes at country and international level described earlier in this document.\(^\text{58}\)

US aid for AIDS

The US currently provides almost half of all international AIDS funding.\(^\text{59}\) A great deal of recent US policy intervention, including US Secretary of State, Colin Powell's, stresses on HIV/AIDS as a security issue, and is invaluable in the global fight against the pandemic. However, one of the largest commitments to fighting HIV/AIDS recently – President Bush's Emergency Plan for AIDS relief – demonstrates the dominance of donor agendas in allocating money for AIDS to the poorest countries. President Bush chose one of the highest-profile platforms for laying out policy priorities, the State of the Union Address in January 2003, to announce that the US would spend $15 billion on fighting the epidemic worldwide.\(^\text{60}\) Although this announcement marks significant extra cash, there remains widespread scepticism over whether all the money will be made available. So far, more money appears to have been agreed than has actually appeared.
Critics argue that this money reveals a preference for bilateral rather than multilateral aid agreements and note the inappropriate role that hardline views on abortion have in determining the response to the epidemic. The bill for this extra funding for AIDS was subject to intensive lobbying from social conservatives, who at first tried to ensure that no money would go to any organisation whose work was closely involved with abortion. They also tried to ensure that conservative, faith-based groups received a good share of the new US funding. The US government – partly because of the intense lobbying of civil society pressure groups with influence in the administration – was unable to adopt the restrictions on abortion providers. Reacting to this failure, the social conservatives denounced the bill. Subsequently, Representative Joseph Pitts and the House Pro-Life Caucus issued a statement of demands (the Pitts amendment), nearly all of which were accepted by the administration. The resulting bill is seen by many as a tangle of US right-wing moralistic conditionalities within a simplistic analysis of what worked in Uganda. On the other hand, it is clear that influential US policy actors intervened to limit the damaging aspects of the bill. And it was US civil society that led in helping to balance the bill from outside government.

The money is to be spent on three core activities: prevention, treatment and care. Uganda’s ABC campaign is to serve as a model for prevention. The ABC approach promotes three behaviours in hierarchical order: firstly, abstinence; secondly, being faithful; and thirdly, if abstinence or fidelity cannot be adopted, using a condom. Of prevention spending, a third has to be on activities promoting abstinence, regardless of the fact that this often dilutes and confuses prevention messages and fails to engage with the realities facing those most at risk from the virus.

While abstinence is an important constituent of many prevention measures, to promote it in isolation is simplistic. To impose quotas on spending in this way, regardless of the cultural context and of the recommendations of those closest to the epidemic, runs counter to all the lessons of what worked in Uganda. It is a clear example of donor agencies clouding the development of more rational, and more locally appropriate, programming. Writing in the Washington Post, Dr David Serwadda, Director of the Institute of Public Health at Makerere University in Kampala, Uganda, commented: “As a physician who has been involved in Uganda’s response to AIDS for 20 years, I fear that one small part of what led to Uganda’s success – promoting sexual abstinence – is being overemphasised in policy debates. While abstinence has played an important role in Uganda, it has not been a magic bullet.”

The Pitts amendment caused outrage amongst civil society activists. Nancy Northup from the Center for Reproductive Rights commented: “[some of the amendment] ties the hands of the organisations on the frontline”. An activist on the regional web discussion forum AF-AIDS wrote: “I am so tired of seeing and talking about donor-driven agendas, about no one asking us poor Africans what we really want to spend funds on. I am grateful, Mr Bush, that you have agreed to give us money, grateful that we are allowed to have abortions even if we use your money, but fed up that we are continually puppeted to your priority areas. This paternalistic charity is not what we need.”

While this US strategy is said to be based on learning from the Uganda experience, the kind of conditionality placed on this funding is in direct contradiction to the central conclusions of that experience, namely that funding needs to support a country-driven process, not define what a country or society should or should not do. The fundamental reason why Uganda has succeeded in its response to HIV/AIDS is that it was able to set its own agenda and response to the epidemic, and was able to mobilise and generate real commitment from all sectors of society for that response.

The Global Fund to Fight AIDS, TB and Malaria (GFATM)

The Global Fund is the most visible manifestation of the current, long overdue and desperately needed international response to HIV/AIDS. In a relatively short space of time it has established both a highly effective leadership role in raising funding for the pandemic, and a sophisticated infrastructure for spending it. This infrastructure has sought to place at its heart principles of in-country ownership.

Based on the idea of Kofi Annan in April 2001, the Fund was brought to life after the UN General Assembly Special Session on HIV/AIDS in autumn 2001, and approved its first round of proposals in 2002. The second round of proposals was approved in January 2003. The creators of the Fund hoped it would become the main funding mechanism channelling cash from heavyweight donors through to the most needy recipients. Its remit is global and it disburses funds on a country basis, mostly for integrated programmes involving a collection of organisations at national level. For many, the Fund provides the best method for balancing the need for a rapid dispersal of cash to fight HIV, whilst ensuring this is done in an accountable manner, with ample participation from local stakeholders.

However, cash for the Fund has not been as forthcoming as originally hoped. Instead of having $10 billion a year for HIV/AIDS, as of September 2003 only $4.7 billion had been pledged for work lasting until 2008. The impact of these shortfalls has been far-reaching. For example, it was announced in February 2003 that the Fund had to ask Caribbean communities to downgrade a proposal they had submitted as it did not have sufficient money to support the whole project. At the World Economic Forum in Davos, the Executive Director of the Fund, Dr Feachem, called for an additional $6 billion.

The strategy of the Fund is founded on exactly the principles of ownership and country-driven strategies that are argued for in this report. How these principles find practical application is another matter.

In each country, funding applications are coordinated through the Country Coordination Mechanism (CCM), which is designed to include broad representation from governments, NGOs, civil society, multilateral and bilateral agencies and the private sector. Where possible, the CCM builds upon pre-existing mechanisms, but in all cases is, at the highest national level, responsible for national multi-partner and multi-sectoral development planning. A senior government official in most cases chairs the CCM.
The CCM submits its proposals to the Technical Review Panel (TRP). This panel is presented as an independent, impartial team of experts appointed by the Board to guarantee the integrity, consistency and transparency of the proposal review process. The TRP reviews applications for the Global Fund’s support and makes recommendations to the Board for final decisions.

The Board seeks to reach consensus on all matters. If this is not possible, action requires two-thirds majorities from two groups of Board members – the first group includes representatives of donor countries and the private sector and foundations, and the second includes representatives of developing countries and NGOs.

The World Bank is the Trustee of the Global Fund. The Trustee’s primary responsibilities include collection, investment and management of funds, disbursement of funds to countries and programmes, and financial reporting. The World Bank will disburse funds on the instruction of the Fund’s Board of Directors. Disbursements from the Fund are expected to be managed by local funding agencies. However, international consultancy firms such as Price Waterhouse Coopers, KPMG and Crown Agents are more often the funding agents.

There are many concerns about the Fund, and these are well documented elsewhere. Below is a summary of some of the key issues relevant to the analysis we are putting forward here.

**Civil society participation**

On top of the shortages of cash for the Fund, there has been a sustained criticism of the Fund by a range of civil society actors. Most NGOs and community based organisations are not taking part in their country’s CCM, due to their lack of capacity and the fact that consultations are poorly structured. One consultant who played a central role in this process for the Great Lakes Region in Africa said, “It’s very difficult to have participation when you have a deadline of two months or six weeks like in the recent call for applications for the Global Fund. Countries knew in advance that it would be very difficult to develop these proposals so they had teams of consultants coming in from World Bank, UN, everywhere to develop these proposals without any real community participation … They want participation, ownership and so on, but then the application process is so rapid that it makes this just about impossible.”

During the 2003 International Conference on AIDS and STIs in Africa (ICASA), a leading international NGO gave a presentation on its participation in the CCM process in many countries. It stressed that to participate in CCMs, civil society groups need strong technical expertise, and that the process is a highly political one. In its experience, some countries are inhospitable to civil society participants within their CCMs.66

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“Bang for buck”

The motto of the Global Fund, says Dr Richard Feachem, is “Raise it, Spend it, Prove it”. The most effective strategies against HIV/AIDS are often those where results only emerge over long periods of time. Funding in the past has generally focused on those strategies where short-term impact can be easily measured – such as condom distribution programmes – at the expense of more multi-faceted programmes. Strategies where results can be measured in the short term are not those which will necessarily have the greatest long-term impact.

Any fund of this kind needs to provide evidence to those who give it money that their money is being spent effectively. However, the pressure from all donors is for their resources to deliver more of a “bang for their buck”. The Global Fund is subject to the same pressures, and inevitably passes those same pressures onto its grantees.

As a result, short-term planning and rushed processes of strategic development have so far typified the Fund’s work. The danger is that placing too much emphasis on “proving it” creates pressures to perform in the short term, possibly at the expense of a longer-term vision.

Participation and communication

Problems also surround the structures and application processes for gaining access to funds. The application process is time-consuming and technical expertise is often needed to complete it – expertise which is often provided by experts outside a country. In addition, money is generally only channelled through the members of the CCM, so inevitably recruitment within this group is itself a politicised process. The present reality in many cases is that a number of organisations who are politically marginalised in some way, or are at the grassroots level, are excluded from participating in the application process. In the third round of proposals, all proposals that were successful in the first round came from CCMs that were chaired by a government official. An in-depth report by the US General Office of Accounting in May 2003 found that information-sharing proved a real problem in CCMs. Given that many CCMs are being chaired by a government official and in the majority of cases the grant has been awarded to a government agency, civil society participation is a critical issue.

Jon Liden of the Global Fund admits: “We are under no illusion that this [CCM] will be perfect the first time round. In a number of countries, working with civil society is not a normal or established way of working. The information-sharing in the CCMs and in potential grant proposal writers in the country needs to be better.”

But he points out that “this is a country procedure and there’s country ownership of the CCMs and therefore this is something that countries themselves have to take responsibility for, including non-governmental organisations.”

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69 Own interview.
Innovation

The record of tackling HIV has not been a good one, and few would claim that we have developed a sufficient collection of methods in AIDS prevention which will, provided proper funding is made available, contain the pandemic. New strategies are needed. The Fund emphasises the importance of using tried and tested methods. Its mechanisms at the level of Board, Technical Review Panel and CCM are not generally selected to recognise and support innovation. Within the legislative framework for the Fund, there is much mention of focusing on best practices, of scaling-up proven interventions, and of complementing and coordinating with national policies. Little of this encourages thinking beyond the register of current mainstream AIDS strategies.

Adding and complimenting

One of the biggest concerns around the Fund is that, not least because it commands so much public and political profile, the resources it mobilises will be reallocated from other development initiatives. Dr Peter Piot, head of UNAIDS, stated clearly in the International AIDS Conference in Barcelona, and together with Jeffrey Sachs more recently within the Global Forum for Health and Development, that if money for the Fund is drawn from existing initiatives, then it is self-defeating. The money donors give to the Fund needs to be additional money; it should not come out of that already pledged to improving health or related development issues.

The Fund needs to complement existing efforts, not to replicate or replace them. The creators of the Fund have been fully aware of this issue, and the concept of “complementarity” is integral to the Fund’s architecture. Although this is central to building an integrated, synergistic impact, there are clear benefits in adding to what is already happening rather than merely complementing it. This could mean expanding the participation base in coordination, implementation and evaluation. It could also be taken to mean supporting the additional types of institutions, beyond government, that are required to shape up and sustain an effective and vibrant national health response. For example, a strong local media engagement with the Fund would complement, and hold to account, government actions as long as this media engagement was “additional” (meaning independently resourced and managed). Working to support inclusive public discourse and genuine local civil society engagement cannot be coordinated by the very institutions and structures that may constrain public debate and discourse on health funding priorities and allocations. There are clearly valuable “additional” actors and functions beyond those that are typically funded or consulted within, for example, national AIDS strategies.

The Fund is a public-private partnership, and although it may be flawed in terms of its mechanisms for civil society participation, it is arguably fairer, more accountable, and more effective than many bilateral AIDS donor mechanisms. Jon Liden, Communications Director of the Fund, confirms that many donors are reluctant to diminish their control over aid: “I think that it is taking parts of the European development establishment more time to come over to the idea of the Global Fund which is fairly radical. The principle of it [the Fund] is that you have grant rounds, that you don’t go through traditional bilateral aid mechanisms but you actually give money directly through grants to programmes run and owned by countries themselves.”
Accessing the Global Fund – a Zambian perspective

The following document was written in 2002 by a Zambian ethnographer commissioned by Panos.

Peter Bwalya lies on his bed in a small mud brick house in Kalingalinga Compound in Zambia's capital, Lusaka. At 29, his life is ending. In the photographs above his bed, Peter appears strong and athletic. One snap shows him in his judo outfit; in another he poses in his football strip surrounded by his teammates. A third photograph is a head-and-shoulders shot, under which in happier times he had written, “Looking good is not my only dream.” Having contracted HIV and now with full-blown AIDS, his dreams have turned into a nightmare; he has grown so weak that he can no longer turn over in his bed without the help of his wife or friends. They do what they can for him, but they cannot understand why there appears to be so little help available for him, especially when they hear constantly in the media that millions of dollars have been given to Zambia for HIV/AIDS and even more millions are expected to arrive any day now.

Peter’s family and friends are not alone in this lack of comprehension. In Lusaka, at the headquarters of the national network for People Living With HIV and AIDS, committee members are also grieving for a close colleague and a pioneer of the network who died a few days ago. Again, like Peter Bwalya, he did not have the means to afford appropriate medical assistance or get access to anti-retroviral therapy. Representatives of the network have in recent months actively participated in the processes leading to the establishment of the GFATM and the Country Coordination Mechanism (CCM). Like other NGOs, they have been struggling to get their case heard for the priorities as they see them. They are waiting for the first disbursement of money from the Fund. They are not optimistic that their priorities will be addressed; their deep sense of frustration and anger is palpable.

Augustine Chella, national vice-chairperson for People Living With HIV in Zambia and their representative on the Zambian CCM, was part of the Second Transitional Working Group which met in Brussels last year prior to the establishment of the Global Fund. He had imagined that the Global Fund would be an exciting initiative in public/private partnership, whereby NGOs would be able to access funds speedily to transform the situation at grassroots level. Instead, access to, and control of, funds remains firmly in government hands where, he fears, corruption and bureaucratic inertia will again take their toll, particularly as, 20 years on, government policy on HIV/AIDS remains in draft form. His anxieties begin with issues of representation:

“The problem is how to get the voices of the Network of Zambian People Living with HIV (NZP+) and other NGOs heard. The NGO representation on the Zambian CCM is totally inadequate. It is totally urban in its orientation. It will be very difficult for CBOs and NGOs working in rural areas to get access to any money. Once again, decisions will be made in Lusaka on behalf of rural dwellers. The Global Fund is an open fund and it is up to each country to set its own priorities but will the voices of the Network of Zambian People Living with HIV and other NGOs be heard? … Such tokenism extends to the level of the Global Fund Board itself where the representative of people living with HIV and the representative of people living with TB have merely observer status, with no right to directly influence decision-making.”
Other members of the network were invited to meetings at the Zambian National AIDS Council (NAC) in connection with the Global Fund, but felt very dissatisfied with the outcome. They felt they were not given sufficient time or opportunity to study and comment on the document finalised there. And they were unclear about the document’s authors. Kennedy, a member of the network and an outreach worker, commented: “There wasn’t enough time. We were called to a meeting. You arrive there. They have already started. You hear: ‘OK we are tackling Priority Number Six. Do you want to add something, or subtract something?’ Do you see? We had no chance to study a draft or anything! They did not really involve us in the decision-making. It was more like we were being used as a rubber stamp.”

Among HIV-positive people, there is a great deal of anger about the manner in which priorities are set and funds are used. They argue that decision-makers at national and international levels fail to draw upon the local knowledge, expertise and experience gained by activists and people living with HIV and AIDS at grassroots level.

Members of the network fail to understand why decision-makers do not spend time in local communities. This would assist them, they argue, to understand the root causes of HIV/AIDS. “If you go into the compounds, you can see the poverty levels. You can see how people are dying”, says Kunyima Banda, Acting Co-ordinator for NZP+, “then you understand the situation better. People at the top should see what is happening on the ground. Without this, it will be difficult for them to make the right decisions. It’s really painful. Most of the funders don’t understand the extent of the problems. The biggest problem is food. Many are dying – not simply because of AIDS but because they have no food. They are hungry and weak and they die like this.”

The network position is clear: the root causes of HIV/AIDS are not being tackled in a sufficiently robust way. Network members are fully aware that the socio-economic context needs to be addressed in any long-term solution to the crisis the HIV/AIDS pandemic has provoked. They repeatedly point to poverty, the lack of employment opportunities and gender relations as among the most salient causes, and contend that these issues have not been given sufficient attention. Those most in need are not receiving the help that should be theirs by right. Suspicion and cynicism are rife. “I think many of those people on top, those making the decisions, well, they are just there for work”, observes Charity, another outreach educator. Kennedy is not alone when he says: “There are those who are living with HIV and there are those who are living from HIV. We feel very bitter.”

For Peter Bwalya, and many thousands more people like him, it is already too late. Among the network of People Living With HIV and AIDS in Zambia who are fighting for the rights of many people who have never heard of the Global Fund, the jury is still out as to whether the lessons of the past have been taken to heart.

Dr Anthony Simpson, Lusaka, 2002
Problems of giving, problems of spending

HIV/AIDS presents a unique challenge to donor organisations. They are under pressure from all sides. They have to prove to their publics what they are doing is having an effect. They need to cut the cost of administration. Yet they also need to consult – to involve as many stakeholders as possible in their decision-making processes. There are few areas of development where spending money and proving impact in a short space of time is an entirely simple process, but the AIDS pandemic presents uniquely complex problems. An epidemic caused by a virus which takes 10 years between infection and disease, is transmitted through sexual contact, which can only be seriously contained through multiple and deep-rooted social changes in society, was always going to be difficult to tackle with conventional strategies. The experience of the pandemic to date demands a serious re-evaluation of how funds are spent, and a courageous set of changes which look less for the short-term bang for the buck and more for the bureaucratically difficult long-term strategies. These need to be rooted in local ownership, and to support multiple mechanisms for supporting the development of such ownership. In this section, we look at some of the real constraints donors face in enabling this to happen.

The Panos survey

In 2002 Panos designed an informal survey to illuminate issues around participation, ownership and accountability within the response to HIV/AIDS. The survey was designed to be a quick and simple gauge of individuals’ perceptions of their organisations’ activities and priorities. Although the data the survey generated does not serve as a “stand-alone” authoritative overview, when taken alongside other information sources it illuminates a number of important issues.

277 people responded to our survey on-line and a further 93 filled in a paper version at the Panos booth at the 14th International AIDS Conference in Barcelona. This survey was interactive, enabling general questions across all participants and more specific questions depending on the background of the participants.

For this purpose we grouped the responses as follows: service providers (NGOs, public sector service providers, grassroots organisations, service-providing faith groups or religious organisations, private sector service providers); community based organisations (HIV/AIDS support networks, AIDS activists or community based organisations); donors (UN agencies, corporate funders, government funders or foundations); media or other (those that did not fall into any of the above categories).

Giving the money: examining donor environments

Donors are answerable to their host governments, or, in the case of private foundations, to their board or the corporation of which they are part. Because of this line of accountability, donors are under intense pressure to prove the impact of their work.
Consequently, high-profile activities and concrete outputs are preferred over less tangible activities. Frans Mom, who works for a Dutch donor organisation, HIVOS, has stated: “I am convinced that there are many foundations and they only work on [a] project basis and [on what] they want to fund, for example distribution of condoms or another very specific activity. That’s what people love to hear.”

The international community needs to be aware that progress will not always be simple to assess, with indicators buried within complex social patterns and emergent trends. The kinds of variable indicators used to mark programming success need to be reappraised. More high-level support is needed for the development of monitoring and evaluation tools for working on enabling communication environments. This would improve both their effectiveness, and their legitimacy within the broader development sector. One problem is that there are a number of frameworks and indices for success. For example, the UNAIDS model is different from the UNICEF model, which is different from the UNFPA model. In order to promote and legitimise more empowering, more effective communication, it is important that senior figures within the multilaterals coordinate at least a series of common assumptions and principles for implementing and monitoring communication activities.

The institutional pressures and constraints on donors differ from one political environment to another. A senior consultant who has worked for the Swedish International Development Cooperation Agency (SIDA), Danish International Development Assistance (DANIDA) and USAID says: “I would make a distinction between the US donor community and many of the European donor communities. USAID, and the large American organisations they support, have strong accountability to Congress. Congress enforces a strong control upon how the money is spent. I think that in the US donor community there really is a ‘bang for buck’ kind of principle where quantifiable results must be shown. The European bilateral have, until recently at least, had a broader range within which they could work, with less politically driven results-orientation.”

But according to a number of commentators the situation in Europe is changing. According to Frans Mom, “We are not sure if our position will last. More and more people say I want to see concrete results, and if you can’t show results you are told to make the thing simple. But this is hard for us because it’s not so simple, and our work takes a longer time.”

For the Scandinavians the situation is similar. In 2002 DANIDA was analysed by the Danish National Auditing Office, which criticised them, saying that they were not sufficiently results-orientated and were not sufficiently able to demonstrate quantifiable results or the impact they were having. According to the consultant for SIDA, DANIDA and USAID, “That is a trend that resonates with what goes on in USAID, an increasingly international trend – with a clear corporate and private sector inspiration.”

This increasingly global trend towards achieving quick, efficient and highly visible results, has driven donors to shorter-term projects – with three years being the most common duration (see Figure 2). But because of the extended periods of time required to set up a programme, and then to evaluate it at the end, even three-year programmes often only run activities for around two. The question is, what can you do in a couple of years that will have a lasting impact on the epidemic? Working towards an environment where change can come from within, and where the roots of the epidemic can be tackled, can take much longer.
Spending the money

As AIDS climbs the policy agenda, it is increasingly absorbed by the machinery of national and international organisations working on development and public health. The liberal outlooks and progressive strategies that characterised early civil society action become subsumed within the more unwieldy hierarchical structures of government or UN decision-making. And as the machinery of the AIDS response becomes more differentiated and elaborate, organisational self-interest can and does come into conflict with the needs of those most affected.

Table 1

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<tr>
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<th>Answered by all donors</th>
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<tr>
<td>totally</td>
<td>6%</td>
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<tr>
<td>almost totally</td>
<td>24%</td>
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<td>37%</td>
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<tr>
<td>very small amount</td>
<td>9%</td>
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<tr>
<td>not at all</td>
<td>3%</td>
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To what extent do institutional, bureaucratic or political constraints detract from your efforts to ensure your work is guided, owned and implemented by communities most affected by HIV/AIDS?

Source: Panos Survey 2002
With larger sums of money being available, the trend is towards dividing the funds between a few recipients for optimum administrative efficiency. The money is often distributed through consortia of partners under the direction of a lead organisation, most often based in a wealthy country. Senior staff in the biggest US-based NGOs describe the competition for funding as intense – and equivalent to the competitive environment within the corporate sector. In one US-based NGO, any project worth less than $2 million was, in their language, “burnt” (abandoned). Pursuing such projects can be inefficient, losing the bigger international NGOs’ “market edge”. In this environment, what role can recipients of development assistance have in creating new AIDS projects?

The sheer amounts of money that donors have to distribute can cause problems. According to one consultant closely involved in these processes: “You get DFID and other organisations getting massive amounts of money, which is distributed in partnership with civil society NGOs. And many NGOs or CBOs in developing countries are made up of just two or three people that are all of a sudden expected to absorb hundreds of thousands of pounds. They don’t have the mechanisms, financial accountability or training to do this ... there are no systems in place to build the capacity of NGOs to use this money effectively. So what happens? It either gets wasted or it goes back into the local government and after that we don’t know what happens to it.”

Often, the problem is not the civil recipients of funding, but donor requirements in the application process. In Botswana, African Comprehensive HIV/AIDS Partnerships (ACHAP), one of the richest in-country donors, with over $20 million to disperse annually, has been criticised for its timidity in distributing funds. According to one small HIV/AIDS support group, a proposal for just $3,000 had to be rewritten three times and it took over eight months to receive a response. The question is, how can an organisation like ACHAP more effectively respond to the needs of grantees, while still remaining accountable to those that give it money?

Another consultant speaks of recent shifts in policy that are supposed to be all about participation, particularly the Poverty Reduction Strategy Papers (PRSPs) and the International Partnership against AIDS in Africa (IPAA): “...these are all very government led. They are all about participation, but in name only. They are not very participatory at all, generally they are led by consultants that come in from overseas and direct the process. It’s done in a very hurried manner because donors give deadlines which have to be abided by.”

Many donor organisations have field offices in the South and they use these to solicit input for many of their major decision-making and strategy development processes. However, as Calle Almedal from UNAIDS points out: “consultations are different from direct involvement in decision-making – in consultations people give advice and hope it is heard, whereas it is in the actual decision-making where the power is exercised”. Of the 43 donors that responded to the Panos survey, only 12.9 per cent consult with the groups vulnerable to HIV/AIDS.
Organisations in the South are at the end of a chain of command that may mean they are answering more to those with the cash than to those in need of services. Most of these organisations (64 per cent of NGOs we surveyed) get their funding from a Northern source or from governments whose health budgets are derived from the donor community. More NGOs and Community Based Organisations (CBOs) that Panos surveyed said their work was determined by their donors than by the communities most affected by HIV/AIDS (see Table 2 below). The donors these NGOs were referring to were mostly Northern based. A quarter of all these organisations reported that they were not sufficiently accountable to the communities they served. And in a separate question, those same NGOs were asked to what extent they felt that their activities were led and “owned” by those most affected: 28 per cent answered “a small amount”, “a very small amount” or “not at all”. Only one in five NGOs surveyed thought that communities affected by HIV/AIDS were adequately represented in general decision-making.

Hakan Seckinelgin, an academic working on HIV/AIDS issues at the London School of Economics, claims that “the issues around which civil society mobilises are still articulated at the global level, not the local”. Clearly “out in the field” those most affected have only a minor voice in steering the process. And, more ironically, in consultations for national strategic plans, for the Global Fund, or other funding and policy processes, NGOs and CBOs are often taken as the “voice of civil society”. When, to some degree, this voice is a hired hand of the North, to what extent are these consultations representative?

The following feature from Panos South Asia highlights the impact of some of these dynamics in India and Nepal.

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<tr>
<td><strong>Who determines what you are doing?</strong></td>
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<td>Answered by all CBOs and NGOs</td>
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<td>all staff in our organisation</td>
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<td>executive of our organisations</td>
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<td>organisations board or council</td>
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<td>our donors</td>
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<td>government</td>
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<tr>
<td>blank</td>
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<td>UN Agency</td>
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Beyond health: a South Asian perspective

In millions of homes and streets across northern India, beginning July 2002, a slick interactive detective serial produced by government agencies in collaboration with the British World Service Trust beams in information about HIV/AIDS, condom use and misconceptions about the disease.

Such programmes are important for providing millions with information and getting them interested in AIDS, but for Sangita, 14, a commercial sex worker on a busy highway in the western Indian state of Rajasthan, the messages have no meaning. “What do I care for a disease that may kill me in five to 10 years when I know I won’t have anything to eat tomorrow if I insist on condom use with my client?” she says.

South Asia is home to 4.2 million cases of people living with HIV, the second-largest prevalence of HIV/AIDS in the world. With an estimated 3.97 million infections, India alone has nearly 10 per cent of all the people living with HIV/AIDS in the world. Donor agencies are pouring in millions of dollars for prevention and control efforts that are evident in hoardings looming out of busy city streets, paintings on buses, street plays, puppet shows, hand bills, rallies, folk songs, spots and soaps on radio and TV, door-to-door campaigns in rural areas and a whole range of information and communication activities centred on the issue.

In Nepal, the government declared 2002 to be the year for a health campaign against HIV/AIDS. But the desired “behaviour change” is still elusive.

A behaviour sentinel survey conducted from March to August 2001 by the National AIDS Control Organisation, the nodal body for prevention and control of HIV/AIDS in India, showed that although an impressive 90.4 per cent of the population was aware of condom use, only a third of males (33.6 per cent) and a quarter of females reported consistent use of condoms with non-regular partners in a 12-month recall period. Again, whereas the awareness of HIV/AIDS was high among female sex workers and their clients, only 17 per cent of female sex workers perceived themselves as being at a high risk of contracting HIV/AIDS.

Similar findings were reported from an evaluation of the Information, Education, Communication component of the national AIDS control programme in Pakistan. The component had significantly increased knowledge and awareness from a low 4 per cent in 1991–92 to 75 per cent in 2001. However, this had not led to behaviour change. Since information on condoms is not permitted through the mass media, a predictably low percentage of the population – less than 1 per cent – mentioned condoms.

In Nepal, Rama, 29, a commercial sex worker in Kathmandu says, “But you see, men just don’t want to use condoms. If we insist, we won’t be able to continue our business … As long as my body functions, I have to earn and save, for who will look after people like us when we become old? Look, people like you will never be able to understand … you have never had to sleep on the streets on an empty stomach.”

It is now widely recognised that the first step towards behaviour change is that people should be able to perceive themselves as vulnerable to HIV/AIDS and express the need to know more about it. Difficult in a region where, based on the dollar-a-day benchmark, 40 per cent of the world’s poor reside. The region accounts for one third of the world’s total population and India alone has more undernourished people than all of sub-Saharan Africa combined. Education, employment, drinking water and nutrition easily assume priority over HIV/AIDS.

That social and economic vulnerabilities lie at the root of extensive commercial sex, population movements (cross-border/rural-urban migration) and trafficking, which fuel the HIV/AIDS epidemic, is now a given. The declaration of commitment at the United Nations General Assembly Special Session (UNGASS) and the UNAIDS HIV/AIDS Communications Framework recognise that HIV/AIDS intervention programmes need to be addressed in the broader framework of poverty, inequity, illiteracy and gender imbalances. But there is a serious gap between policy formulation and implementation.

In practice, isolated, top-down information dissemination seems to be the preferred criteria still. Messages reading “I care, do you? Let’s join hands against HIV/AIDS” dot the region. But for Manga, 21, an HIV-positive widow with three children in the southern Indian state of Andhra Pradesh, “Before my husband got the disease, I had heard its name and saw an advertisement on it on television. But I didn’t know the details of how one acquired the infection. I thought it was prevalent in other areas, not here.”

Participation of communities in generating information geared to their needs and involvement of stakeholders is absent at different levels. In India, the World Bank funded National AIDS Control Programme provides guidelines to the State AIDS Control Programmes in conducting communication campaigns, implementing targeted interventions, introducing preventive education in the school system and setting up care and support activities. The implementing NGOs also centre their activities on the guidelines without involving the community. Training is lecture-based using existing training manuals, awareness campaigns are judged by numbers and the needs of the community get lost due to the emphasis on quantity.

“The State AIDS Programme officers come from an administrative background with very little or no experience in implementing intervention programmes and look up to the centre to provide them with guidelines. The rigid guidelines make it impossible for us to involve the community”, says Mariette Correa, NGO adviser in the Goa State AIDS Control Society, India. In Goa, the State AIDS Control Programme involved a women’s collective NGO to plan and implement a project on HIV/AIDS/STD prevention and control. Yet the NGO was asked to either withdraw or change the beneficiaries since women do not find a mention in the vulnerable groups specified under the targeted intervention component by the World Bank. Now the NGO is involved in distributing condoms to migrant workers, which is not a need.

Food and Agriculture Agency (1999)
“All donor agencies recognise in principle the involvement of beneficiaries yet doubt their capacities in guiding, implementing and managing programs”, says a programme manager from UNAIDS Nepal. The NGOs too need to sustain themselves and therefore bend down to the guidelines laid by donor agencies, she adds.

But the key to framing and implementing successful communication strategies on HIV/AIDS seems to lie in letting communities set their own agendas. These must tackle the problem within context-specific frameworks that take into account the core issues that drive the epidemic in the region.

Mitu Varma
Anushree Mishra
Panos South Asia
Crucial to our analysis is an emphasis on which voices are heard and which are excluded in AIDS decision-making. At present, the process through which the agenda on HIV/AIDS is set excludes the voices of those most affected. For example, in a number of multilateral AIDS funding mechanisms, including the Global Fund, and the World Bank’s Multi-Country AIDS Programme, “national ownership” is taken to mean the centrality of mechanisms such as the National AIDS Council, AIDS Commission and, in the case of the Global Fund, the Country Coordination Mechanism. However, most often these bodies are answerable to government and the voice of civil society is often unsatisfactorily represented. Bilateral and multilateral donor agencies need clear legal and operational frameworks for ensuring civil society participation, and these agencies should not be averse to seeking wider points of contact than the National AIDS Councils, or equivalent agencies, within their recipient countries.

International policy processes need to do more to incorporate the views of those they work with, and, crucially, to enable these views to emerge and be articulated.

There are signs that this thinking may be beginning to permeate into the processes by which funding is allocated. The British government’s Department for International Development (DFID) is supporting some innovative thinking on more empowering communication, both within the department and also by supporting a number of key partners. USAID recently announced allocation criteria for its next round of HIV communication funds. The organisation is now also stressing the need to look at individuals’ behaviour in the context of all the social, economic and environmental factors that might be at play. As USAID’s request for applications for the global communication funds states:

“Communication activities that are designed to address more fundamental aspects of the social context in which health behaviours occur may contribute to greater successes. For example, enhancing participation in civic life ultimately contributes to community mobilization that advances public policies that promote health. The Rockefeller Foundation’s ‘Communication for Social Change’ initiative, for example, has demonstrated that social capital is a bona fide approach and outcome.”

Organisations such as UNICEF, Panos, the Communication Initiative, and the Health Exchange are among those which are developing and implementing approaches informed by Communication for Social Change. A number of exciting partnerships across these organisations are evolving. One major new development is the Communication for Social Change Consortium, a network of practitioners, researchers and scholars dedicated to developing and applying the frameworks and principles mentioned above. All these organisations and partnerships will help to galvanise action around these important communication principles.

**Focusing on voice**

AIDS moves through the fracture points of society, targeting those whose gender means they can’t negotiate safer sex, whose economic situation means that sex is sold, and areas where social norms push sex between men underground. It targets communities where high unemployment or low wages create environments where drug injection or sexual risk offer some of the only means of diversion or self expression. The epidemic targets communities undergoing rapid social change, conflict or displacement. Weak education systems, dilapidated or dangerous health systems, places where the media are restricted from effective reporting, are all environments in which AIDS flourishes most successfully. The fact that the people most affected by HIV/AIDS are poorly represented in shaping the way in which governments and international organisations deal with the problem, is of no surprise. AIDS has always affected the poor and marginalised most, and these are the groups, almost by definition, who are outside the kinds of policy discussions that shape their societies.

The lessons of Uganda, Senegal and Thailand are that while creating widespread public awareness and understanding of HIV/AIDS was a critical part of any effective solution, equally important was that all levels of society formulated their own responses to the epidemic. The reception of AIDS messages was complemented by people being able to speak out about it – to talk between themselves, to make demands at the national level. This debate and discussion was referenced to and informed by trusted voices in government and in the local universities. Action, whether in sexual behaviours or in the myriad social interactions which lead to social change, emerged from discussion and debate in society, a debate driven by a multitude of voices.

Communication strategies need to be redirected so that they give prominence to the creation of communication environments which encourage interpersonal communication, dialogue and debate, and which focus as much on providing a voice to those most affected by HIV as they do on educating them through messages. The evidence increasingly suggests that only when people become truly engaged in discussions and talking about HIV, does real individual and social change come about.

The logic of HIV distribution is tightly meshed within broader systems of inequality, and any attempt to overcome the health issues without tackling the underlying ones represents only a superficial fix. HIV communication is no exception. Messages about AIDS prevention, international campaigns on AIDS and men or AIDS and stigma are valuable, but are insufficient when divorced from approaches that respond to the underlying structural issues. Rather, there is an urgent need for supporting interventions that facilitate communication on AIDS in a manner that adapts and responds to the inequalities within each setting. There are opportunities for enabling those most affected by the epidemic to bridge some of the communication divides that are both a cause and consequence of these inequalities.

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These bridging mechanisms may take the form of a media environment in which a greater plurality of voices and world views, including those of the disenfranchised, is expressed. They may take the form of policy environments more open to the ideas and inputs of those stakeholders most affected by HIV/AIDS.

The forces of AIDS activism, fuelled by the desperation of those whose lives have been harmed by AIDS, or by the energy and anger of those working to tackle HIV/AIDS, can bridge some of these inequalities. Where local activism has caught hold, the results, as we have seen, are inspiring. But for local activism to flourish where there is not already a politicised civil society, an environment needs to be created in which dialogue and open discussion can take place, where communities of interest can emerge, and where the views of those with the most at stake in public debate on AIDS can be heard.

In emphasising the importance of building enabling communication environments, we are not talking about developing new types of health messages, no matter how empowering and context sensitive. Instead we are focusing attention on the networks, channels and social infrastructure through which talk, debate, advocacy and mobilisation against HIV/AIDS can flourish. As Elizabeth Fox from USAID stated in a recent presentation, “A finely crafted message on decreasing sexual partners is useless in a world where young women have no access to the media, or, even worse, have no power over their partners.”

Using examples of past success, it is possible to start teasing out the different positive aspects of HIV communication environments, though at this stage, and with the resources currently available to develop this work, this is far from being an exact science. More research and analysis within this area are urgently needed.

### Communication for access to treatments

Before sketching out some of the broad areas in which change is most needed, it is important to note that the issues surrounding treatment, particularly on accessing the increasingly available anti-retrovirals, are likely to pose some of the greatest challenges for HIV communication. From counselling, support groups, peer education and “treatment literacy”, to essential drug lists and the negotiation of agreements to make generic drugs available, a number of policy and programming priorities vie for attention. Our argument remains relevant – particularly in the context of the challenges and opportunities which more widespread availability of treatments may bring. The priorities we advocate below are drawn from the extraordinary experiences of communities that successfully demanded AIDS treatments. Our argument is that as well as informing communities on drugs, supporting adherence, and working at a policy level to bring the drugs to those who need them, building enabling communication environments remains crucial. There is a clear imperative to equip those most affected with the means to demand drugs, to hold policymakers to their promises on treatments, and to inject some of the anger and impatience felt by communities into policy discussions at the very highest levels.

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Laying out the constituents of “enabling communication environments” could be done in numerous ways. For simplicity and clarity, we focus on what can happen at a local level, emphasising three dimensions where change is most needed.

1 There is a need for local policy environments that can openly address the problem of HIV/AIDS, provide leadership, accommodate civil society action, and that are responsive and accountable to the communities most affected.

2 There is a need to encourage the development of local media that allows for the dissemination of appropriate information, that provides a platform for public debate, and that can serve as a mechanism for holding policymakers to account.

3 There is a clear need for a civil society to have the right to free speech protected by law, to have the tools and the capacity to make its views heard to policymakers, and to have the ability to access national or international media.

This is far from a final analysis or an exhaustive list, but lays down in concrete terms some principal areas for change. We also need to stress that these have been framed neither as policy recommendations, nor as a checklist for civil society advocacy. We anticipate that the readers of this document will be working, or planning to work, within the response to HIV/AIDS, but that they will come from a number of different areas: policy, donor, civil society and more. To accommodate this disparate group of audiences the points below list what needs to change, but do not pre-guess the methods that different groups might use to bring about these changes.
Within an ideal communication environment, AIDS policy would be open to public scrutiny, input and accountability. Good governance on any issue can be measured with reference to political process, civil and political rights, media independence, civil service independence and competence, rule of law, and corruption. Governance on HIV/AIDS is no exception. Where AIDS decision-making is not open, the circle of those who are able to provide insights and information is reduced, leading to less-informed policy. On the other hand, where political process allows for the participation of civil society, where the media can speak out about HIV/AIDS issues, where individuals have rights to freedom of speech, freedom of association and freedom of movement protected by law; then positive policy environments for successful responses to HIV/AIDS can follow.

We have shown how maintaining the emphasis on political leadership is crucial, while the further up the hierarchy that political commitment and a willingness to speak out about HIV go, the more effective the result seems to be. However, focusing on political leadership is not enough, and all settings require a much broader base of support, which includes civil society and the private sector, if they are to achieve an effective response. Also, our analysis highlights the importance of working with existing civil society networks, supporting their efforts rather than funding organisations that have emerged as resources have been made available.

We need a renewed emphasis on communication, media and information. This will require reappraisal of current multi-sectoral responses. Rather than embracing yet another government or private sector actor within the response, we need to align existing responses around a motif of community mobilisation, participation and action. While public or private information, media and communications sectors are already central to most national responses, their role should be extended from information dissemination to actively accommodating a broader series of debates and dialogues.

At the level of programming, a clear policy implication emerging from this analysis is that we need renewed emphasis on programmes and activities that focus on communication environments. We highlight the importance of programming where debate, dialogue and complementary forms of communication work are given emphasis: community radio, strengthening traditional fora for community dialogue, providing communications training and support for those most affected, are just a few examples of this kind of programming.

Critical examination of Information and Communication Technology (ICT) policy should address the avenues through which AIDS stakeholders can access information, and air their views within the public domain. However, as one USAID commentator notes, “Development communication starts with structure, participation and content and then finds the right technology, or technologies. Technology is not the beginning and not the end, it is a tool. As an old friend taught me many years ago, you cannot blame the airplane for not getting you there on time.”

An open, inclusive, accountable policy environment can support the kind of dialogue and public mobilisation typifying successful responses to HIV/AIDS.
Communication from a human rights perspective – a useful policy reference

Models of human rights within HIV communication have been elaborated as a policy and programming resource, particularly by UNICEF in Eastern and Southern Africa.82

“Communication is explicitly recognised as both a right and a means to claiming other rights. Communication occurs constantly as people make daily decisions, explore strategies for surviving and coping, discuss norms and standards to apply in their communities, absorb and apply new information and experience and affirm themselves…

In communities, however, many claim holders – especially women, young people, the poor and the sick – are unable to communicate effectively or to participate in decision-making equally because of their low social or economic status, and/or their limited access to information and communication technology. Communication from a human-rights perspective seeks to give a voice to these voiceless claim holders, so they can express themselves and be heard in modes that are indigenous and authentic to them. Equally, it seeks to enable duty bearers to listen generatively to the opinions of all claims holders, especially the marginalised and disempowered, so that all viewpoints can be considered and included in decision-making.”83

UNICEF has implemented communication strategies based on this approach in Uganda, Swaziland and Tanzania. Together with UNAIDS, it is helping National AIDS Control agencies to develop communication strategies based on human rights principles in Mozambique, Lesotho, Tanzania and Ethiopia.

This work is informed by the UNAIDS/OCHCR (Office of the UN High Commissioner for Human Rights) 2002 guidelines on HIV/AIDS and human rights.84 From these guidelines a number of points are particularly relevant in terms of policy priorities for building enabling communication environments.

These guidelines stress the importance of “coordinated, participatory, transparent and accountable approaches”. They emphasise that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation as well as protection for civil society and community groups. The importance of HIV information is recognised, with “adequate HIV prevention and care information” presented as a human rights issue.

The guidelines note that states should implement and support legal support services that will educate people affected by HIV/AIDS about their rights, and provide free legal services to enforce those rights. Furthermore, states and civil society are urged to promote a supportive and enabling environment for vulnerable groups by addressing underlying prejudices and inequalities. Community dialogue is emphasised throughout, as is support for community groups and engagement with the media.

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82 Ford, Neil and Chorlton, Rozanne (UNICEF) with Odallo, Dan (UNAIDS) (forthcoming 2003)


We urge a critical examination of the role of the media, one that goes much further than portraying the media primarily as a vehicle for information dissemination. Information is crucial, but so too are the ways in which it is passed on and which voices are granted credibility. For HIV/AIDS, where stigma, gender and other forms of inequality play such key roles, the media ideally can provide a forum where a plurality of voices is heard, and discrimination based on prejudice or socio-economic status is set aside. The media's function of challenging government policies and campaigns is also important – illustrated by national and global media coverage of the South African government’s recent dismissive policies relating to AZT, a live saving anti-retroviral drug.\(^8\)

The media itself is changing fast. Globalisation, privatisation and deregulation of the media industries has proceeded rapidly. The kind of liberalised, democratic, complex media that began to characterise Uganda in the 1980s is increasingly typical. This media information revolution, arguably more complex and pervasive than the information technology revolution, increasingly provides opportunities for many perspectives and voices to be heard. This series of changes is characterised by multiple sources of information, including growing numbers of local radio stations and print publications. These are increasingly often privately owned in countries once dominated by the state media. There is television in places where there was none before, with multiple, usually commercial, channels, where once there was only one. The new technologies of the internet and mobile telephones are also changing how people communicate. In place of limited information coming from a few authoritative sources, many messages are now passed between growing numbers of individuals and organisations in increasingly networked societies. It has become far more difficult to target information and fewer sources are automatically accepted as authoritative.

These changes present both opportunities and problems for HIV/AIDS action. There is potential for these changes to bring greater pluralism, access to information, democratisation and responsiveness to consumers’ needs. But these changes also bring a highly advertising-driven and commercial media, prone to sensationalism and often highly sexualised. There has been an explosion of radio stations in many developing countries, and an associated upsurge in talk radio. Discussion programmes, phone-ins and other talk-based formats are increasingly popular and provide some of the most powerful examples of development programming. Stories told by HIV-positive people, sympathetically treated on a radio programme, can arguably have far more effect than more conventional communication messages, and there are many examples of this happening. Relatively little support and emphasis is given to such interactive forms of media relative to the support given to media that merely disseminates information.

In this context, community media is an area which deserves far greater attention in terms of implications for health. Too often, budgets and support for community broadcasting initiatives is given without due attention to the potential this media has for strengthening communication environments for health.

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In this sense, strategies which aim to create a communication environment in which HIV/AIDS can be more openly discussed, and where those most affected by the pandemic can be heard in the public arena, are likely to have a significant impact. Helping to improve the media regulatory regime, licensing, regulatory bodies, codes of practice, and complaints procedures, are all critical to the media providing enabling communication environments. This extends to strategy, spending and priorities, management and organisation, infrastructure, staffing and equipment and building independent capacity. AIDS, as the number one development priority for many countries in the South, should be an issue on which the performance of the local media is judged, with the necessary improvements being made to regulatory or legislative frameworks wherever necessary.

While broadening opportunities for public debate and expression on the media is one option, we stress that other types of media programming which air the concerns and priorities of audiences are also important. Paulo Freire, an educationalist whose thinking permeates much of the communication theory outlined above, has said that a lot of communication “does not swim in the cultural waters of the people”.

Documentaries, news reporting, investigative journalism and dedicated features on HIV/AIDS all have a role to play in opening up communication. So too does more lifestyle programming, particularly where it resonates with local popular culture.

Before clear programming priorities for working with the media can be presented, an important knowledge gap needs to be addressed. Focused research, supported by high-level policy actors, is needed to assess how knowledge, attitudes and behaviour are influenced by the media in today’s increasingly complex and crowded communication environments. Information on AIDS may be received from many sources, and often competes for legitimacy. The differing discourses on condom use emerging from religious or health sector sources are a frequent example of this. In these environments, knowledge and understanding can be fragmented – with no single authority granted total credibility. The net effect of media exposure to AIDS messages may be more to reinforce generalised narratives of self, body and risk than to impart a unified understanding of the social and biological aspects of the epidemic. Panos, the World Association of Community Radio Broadcasters (AMARC) and others are conducting research on the broadcasting environments in different countries, and how this links to broader developmental concerns, with a small project examining implications for AIDS. More work is urgently needed in this area.

The ideal of public service broadcasting is “to make good programmes popular and popular programmes good”. Popular does not mean that the stories lack depth or substance – and in good media engagement with AIDS, issues can be as topical and gripping as they are significant in terms of health. Caution, however, needs to be exercised when making generalising statements about how this is best achieved. While balance, fairness and integrity can be considered universal media ideals, the challenge is to recognise that cultural context will determine other aspects of media production. For example, not all aspects of Western production formulae will be universally applicable to all settings. Broad media ideals can be taken as shared, whereas the final shaping of media outputs depends on audience and socio-cultural context.
A key challenge involves supporting investigative journalism. In a democracy a key role of a free press is that of disclosure – exposing fraud, corruption and malpractice and championing the causes of the vulnerable. This is a central tool for extending public accountability and transparency, and in turn a powerful catalyst for local ownership and control of the response to the epidemic. Where investigative journalism on HIV/AIDS is conducted irresponsibly or unprofessionally, damaging implications for future journalistic access to information and policy circles can quickly follow. Another challenge arises because in some cultures, deference to leaders and humility in approaching senior policymakers is deeply engrained. Here, investigative journalism can appear antagonistic, conflictive and culturally insensitive. Both decision-makers and the media in these situations need to be invited into a dialogue about the appropriate boundaries for investigative media.

Media training

- A key challenge in media training involves incentives. While skill enhancement, education and networking are incentive enough for some media personnel, in some contexts this is not the case. Encouraging market access, particularly to well-paying, prestigious Northern media outlets, can be more effective than direct financial incentives or the development of awards.

- Often media training courses take the form of one-off seminars or a short series of workshops. Courses should be regular, well structured, and aimed at media personnel with similar levels of experience and expertise.

- Media training should be developed around career trajectories, clearly fitting in to participants’ career pathways.

- Where a number of different organisations are working with the media on health, there is a need to coordinate efforts and to provide consistency and continuity. Also, where possible, media training should integrate with the work of media training institutions and on-the-job in-house training.

- Courses should be supported with well-presented learning materials, as these live on well after the training ceases. Reporters benefiting from Panos’ media training on AIDS still tell us they refer to the course folders years later.

- The need to provide resources for the investigation of stories must be emphasised.88 Panos’ own experience of working with the media on HIV confirms that providing skills and information is good, but the effect can be multiplied if journalists are given the resources to fund extra research.

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National governments, donors, UN agencies and the private sector (including pharmaceutical companies) all play a powerful role in shaping the response to the epidemic. Civil society plays an invaluable role as a balance and supplement to these institutional players. It draws the HIV/AIDS issues and problems faced by private individuals into the public sphere, providing “the structured setting where cultural and ideological contest or negotiation takes place”. By civil society action, AIDS – which through stigma, or through the cultural sensitivities associated with human sexuality, is so often private – is made political.

For civil society to function at its most effective, certain conditions need to be met in the policy and media spheres: “Freedom of assembly, association and expression, a protected private life, a political system which operates with freely organised political parties and general elections, and a democratically regulated media system are prerequisites for liberal public spheres, which cannot flourish under authoritarian conditions.”

However, in many of the countries with the greatest burden of AIDS, effective civil society action is constrained by some or all of these factors. In particular, it has been claimed that civil society and the state in sub-Saharan Africa are too interconnected for truly fair “contest or negotiation”. According to Patric Chabal, University of London, “A notion of civil society can only apply if there is meaningful institutional separation between a well-organised civil society and a relatively autonomous bureaucratic state. What can be observed in sub-Saharan Africa … is the interpenetration of the one by the other.”

This does not mean that civil society can only function in ideal environments. There are many examples which show that civil society response can push forwards the HIV/AIDS agenda despite the local media and policy environments – the Anti-Apartheid movement being the most notable example of recent decades. The recent HIV/AIDS marches and protests by Chinese activists and affected groups – despite the government-led human rights abuses these induced – are another pertinent example. Where community groups and other non-governmental and non-commercial organisations and activists have sufficient energy, support, leadership and vision, and where there is an adequate level of education and resources, then restrictive policy and media environments can be broken through.

Our analysis highlights the power dynamics between donors and civil society. It is crucial that civil society defends its own agendas. The strategy should be to persuade donors of the relevance of civil society objectives, and to raise funds based on these arguments, rather than adapt to donor agendas.

As a measure of ensuring they have the freedom to set their own agendas, civil society organisations need to maintain a diverse range of income sources, and regularly assess their independence from national government, donors or commercial interests.

The provision of information is key – as uninformed civil society action can be as harmful and stigmatising as that of national governments and tabloid media. For example, protests outside the recent 13th ICASA Conference in Nairobi explicitly blamed women for the spread of HIV/AIDS, militating against years of work for a more gender equitable approach to the issue.

Information provision should come from a plurality of sources in order to have as much validity, in the eyes of as many people, as possible. The key is not to silence the voices of militant groups, but to create an environment where the information and skills are available to groups able to articulate and balance all sides of the arguments.
Part of the issue here is the struggle for visibility. Within today’s crowded information and communication environment, one of the key challenges is to be seen and heard in the media. This entails competing with policymakers, celebrities and other vocal organisations which are often granted more access to the media. This is illustrated by the use of publicity stunts – well demonstrated by Treatment Access Campaign’s tactics of taking the bodies of their dead members to the gates of parliament, or ACT-UP’s disruption of AIDS conferences and attacks on the property of pharmaceutical companies. Civil society groups have a whole armoury of methods at their disposal, from formal policy and media briefings to large-scale civil disobedience. While not condoning illegal action, the key is to marry the appropriate methods to each context.

AIDS activism of this sort is informed by increasingly sophisticated political education and uses lobbyist techniques with calibrated levels of engagement. South Africa has a number of examples of such activism, many of which are being successfully exported to other parts of the continent. According to UNAIDS communication expert, Bunmi Makinwa, this largely “Western” orientation of AIDS activism poses challenges to cultures that are not familiar nor comfortable with “loud noises” against the leadership. This process requires sustained attention to ensure activism is increasingly effective, yet appropriate to cultural context.

As we have shown in our examples of past successes, where a strong political consciousness and sense of shared purpose exist in a society, there is a strong platform from which to fight HIV/AIDS. The significance of this point cannot be stressed enough. A critical challenge facing many of us is not to fall into the routine of “business as usual”, taking a string of contracts from national government or overseas donors without mobilising as an effective political force. Effective communication environments for HIV/AIDS require engaged, critical, political civil society involvement. Similarly, there are many strong local community movements that do not place AIDS high on their agendas. The question is how to galvanise these political movements and social groups within the fight against AIDS.

More could be done to enable civil society to share lessons, issues and concerns on the most effective ways to engage with AIDS. The Communication Initiative is an example of a broader network and platform for sharing lessons and experiences and debating communication policy. It represents a partnership of development organisations, working to share the advantages of communication for international development. An example of building communication between different civil society organisations is the concept of “Twinning”. Twinning, as supported by the Canadian International Development Agency (CIDA) and Interagency Coalition on AIDS and Development (ICAD) and facilitated by the Communication Initiative, describes a formal, substantive collaboration between two or more organisations anywhere in the world. It is a process in which AIDS Service Organisations (ASOs), NGOs, research and other institutions come together to contribute to each other’s work and to learn from each other’s experiences.

92 For more information on twinning check The Communication Initiative site http://www.comminit.com/
We have noted that social networks and the quality and quantity of social interaction at a community level appears to predicate greater HIV awareness and behaviour change. While changes at the media and policy level will help to create environments where this social interaction can occur, ultimately civil society in general, and community groups in particular, will be responsible for catalysing and maintaining it. This is still an emergent area of research and thinking, yet a legitimate priority for civil society would be to shape activities around public dialogue and to reinforce existing social networks. Work that strengthens community interaction concerning HIV/AIDS and that creates environments in which talk filters through networks of faith groups, women’s groups, youth groups and the myriad other informal channels of communication, all deserves to be given priority.
So far the principles articulated in the above forums have found insufficient purchase in the reality of ongoing cycles of calls for applications and donor funding. We have argued that the response to HIV/AIDS so far has been entirely inadequate, both in terms of the resources spent and the strategies adopted. We have argued that there is little evidence of a long-term plan for tackling HIV/AIDS, and that donors are poorly placed to support initiatives that are both empowering and sustainable. Rather, there has been an emphasis on short-term, highly visible interventions where impact is measured by overly narrow criteria. Even the most innovative approaches, seeming to offer the greatest hope for a scaled-up, integrated response – such as the Global Fund – operate within constraints and mechanisms that limit public ownership, accountability and the empowerment of civil society.

While donors need to maintain the ethic of spending money wisely, this needs to be balanced with a clearer recognition that the epidemic, with all its complex determinants, will not be turned around within a short space of time. Talk of “emergency responses” is welcome in terms of its sense of urgency, but not if this implies that these responses will bring immediate results with short-term action. AIDS is not an emergency, but a development crisis, emerging over a long period of time and requiring sustained attention and energy to tackle it. A great deal of additional funding is required, not only over a few years but over decades. In this context, rather than an emergency response, there needs to be a clear, long-term strategy where real and sustainable results are only likely to emerge in the long term.

In this document we have shown how various “successes” within the past 20 years of fighting HIV/AIDS were rooted within local contexts, owned by local communities, yet critically engaged with national or international policy and practice. While external support was important and increasingly critical in enabling these responses, the fundamental determinant of success was that ownership and agenda setting were established within each country, not only from government but from many sectors of society.
This document has shown that there are several obstacles to learning from past lessons, and our analysis of funds being made available by the US and the Global Fund, and within other bilateral processes, illustrates some of these. Clearly, we need greater efforts to prove the impact and legitimacy of more empowering communication methodologies. Donors need to invest in this process. We also need programming that goes beyond health information, education and communication to address the social channels, networks and infrastructure that together create and sustain informed, inclusive dialogue and debate on HIV/AIDS. We argue that local ownership, sustained community mobilisation, political engagement and other characteristics of past success stories, are all best fostered through supporting an enabling communication environment.

For policymakers, we have outlined a number of priority areas where more research is required, and more rigorous frameworks need to be developed. It is hoped that these points will penetrate the development of new policy, and may consolidate what is still far from being a robust new paradigm, but is increasingly important emergent thinking.

For those working with the media, we have advocated an appreciation and support of all the media's roles in response to HIV/AIDS. Far broader than information dissemination, the media's role in AIDS governance and the provision of a forum for debate are in urgent need of consolidation and support.

Finally, we pointed to the centrality of civil society engagement and ownership of the response to HIV/AIDS. We looked at some of the current processes and principles that those working within, or supporting, civil society could usefully address to better fulfil their role in today's environment.

None of this constitutes a recommendation to abandon past principles and methods, but instead to build support and resources for those working, in the name of public health, to build the capacity of the media, to enable civil society dialogue, and to fight for transparent, accountable and participatory policy environments. We offer more a collection of debates for continuation, rather than a precise treatise for the way forwards. But the hope is that we add our voices to those of others who are calling out for some fresh thinking and courageous action after the past 20 years of fighting AIDS.