

Critical Challenges in HIV Communication

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Introduction

More energy, money and international attention is now being focused on HIV/AIDS than on any other global public health issue. A pandemic that was being quietly forgotten by the global community only three years ago has hurtled up national and international policy agendas.

Panos has been chronicling and providing analysis of the responses to this epidemic for 16 years – almost since its start. We have never known a time when fighting the pandemic has been such a global policy priority. Determined, courageous, and insistent advocacy by people at the highest level of governments, within the UN, among donors and by an increasingly organised global civil society and among grassroots communities, has succeeded in making the response to this epidemic an urgent international priority.

Equally, there has never been a time when so much energy translates into so little hope. We believe – and the feeling seems widely shared – that the energy and commitment currently focused on fighting HIV/AIDS is in grave danger of being wasted. If coherent, robust strategies are not directed at the root causes of the epidemic, rather than the symptoms, then the same level of energy and attention may never again be catalysed.

This paper argues that the history of the AIDS pandemic provides us with clear guidelines for future action. It also presents findings from a Panos survey which suggests that, particularly in donor terms, we are some way from putting those guidelines into practice.

Summarising lessons

Probably the most successful single mobilisation against HIV/AIDS was the Gay movement of the early 1980s. This was effective in educating itself, campaigning for recognition, destigmatising HIV/AIDS and

securing resources for treatments. Although it failed to muster support for the South, its success in mobilising from the grassroots upwards, taking ownership of the issues and driving its own response serves as an example from which lessons should have been learnt.

For many years now, the international AIDS community has pointed to a small group of countries – principally Uganda, Thailand and Senegal – as success stories. They have successfully contained or made substantial impacts in slowing the spread of HIV. While debate continues on the reasons for their success (and even at times about how successful they have actually been) the foundation for effective action was the same as that on which the social movements in the North were founded.

All three had this in common: a relatively free and open media which had the capacity to report on the epidemic intelligently and portray a range of perspectives; a dynamic and active civil society; an engaged political leadership or at least one susceptible to social and political pressure; and a set of national institutions (government, medical, research, media, non-governmental) that could, through widespread public debate, construct their own analysis of the epidemic. Such a debate tended to focus not simply on sexual behaviour, but on a host of underlying issues including gender inequality, discrimination, marginalisation and poverty.

Opinions differ as to the extent, but there is general agreement that the experiences of these countries have critical lessons for today's response – lessons that are too often being ignored. The dissemination of knowledge on how HIV was spread was critical, but educational and other HIV/AIDS activities were built on a foundation of ownership, debate, and action that emerged from within the country, rather than in response to incentives or initiatives from outside it.

The situation today

In December 2001, Panos facilitated the Communication for Development Roundtable meeting on behalf of UNFPA, UNICEF and the Rockefeller Foundation. This is a biannual event bringing together UN agencies, donors and senior communication practitioners to discuss HIV Communication. The meeting reached a radical conclusion – namely that the response to HIV/AIDS, while sometimes highly effective and participatory, is too often donor-led, narrowly focused, short-term and uncoordinated. It favours quick-fix solutions rather than the deep-rooted social change needed to turn around the epidemic.

Many participants pointed out that informed public debate, a robust civil society response to HIV, and other horizontal efforts, generally take second place to externally conceived and vertically imposed processes. The Roundtable stressed how the lessons of history have been insufficiently learnt – a failure that is having consequences for every aspect of the response to HIV/AIDS. Indeed, many at the Roundtable argued that donor strategies often stifled local responses and agenda-setting rather than supported them.

Building upon this work, and to maintain momentum within international policy debates on these issues, Panos followed the Roundtable with a survey of organisations involved in AIDS policy, funding, service provision and media. (see box on page 6). The full results of this survey will shortly be released in a Panos report on these issues; the following is a brief discussion of some key points.

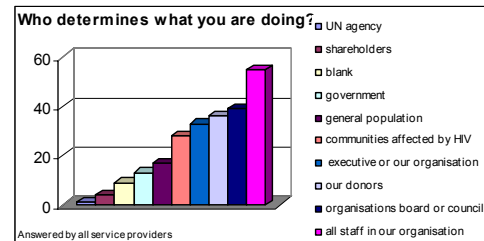
Agenda setting and accountability

The survey helped to illuminate the patterns of influence and processes of agenda-setting that shape the response to HIV/AIDS.

Only 24% of the 277 people surveyed thought that communities affected by HIV/AIDS were adequately represented in general decision making.

Service organisations accounted for almost half of all those that responded. Of these service organisations, most say that their work is determined through internal

consultation. On the other hand, more said that their work was determined by their donors – mostly northern based - than by the communities most affected by HIV/AIDS.



All service organisations were asked to what extent they felt that their activities were led and “owned” by those most affected. While only 28% answered that such ownership was limited or non-existent, our more qualitative work with those most affected by HIV/AIDS – documented in the forthcoming Panos Report on HIV Communication – indicate the problems of ownership are far more acute.

For a community to take real ownership of the problem of AIDS, people have to see that decision makers within government and HIV/AIDS service organisations are accountable. In the Panos survey, 22% of all HIV/AIDS service organisations and community groups felt that their organisations were not accountable enough to the communities they served. Only a fifth answered that they were completely accountable.

Our figures offer a tentative indication that both *what* and *how* information is disseminated maybe determined in the North. Internationally, most organisations running information dissemination activities were funded from the north and primarily aimed to reach southern audiences.

Of northern based service providers that are running information dissemination activities for southern based audiences, 44% make their decisions in headquarters in the North. Many of these organisations were among the biggest spenders of all those surveyed.

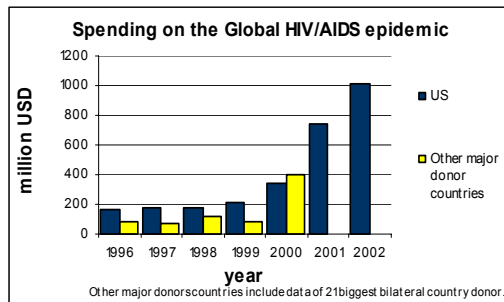
Out of all southern based service providers conducting information dissemination activities, 78% were funded by agencies based in the North. Of these same service providers 34% openly acknowledged that

their donors determine the work that they are doing.

Donor constraints

HIV/AIDS is not unique in requiring a response that is driven from and owned by developing country societies. Most mainstream development strategies – including the Poverty Reduction Strategy processes (PRSPs) being promoted by the World Bank, and the New Economic Partnership for African Development (NEPAD) – have principles of ownership and agenda setting at their core. Whether these principles are translating into practice is another debate. However, clearly within the field of HIV/AIDS, principles of ownership and agenda setting are, we argue, particularly critical, and yet to find purchase within the global response. Conversely, many current strategies seem to be undermining locally owned and driven responses.

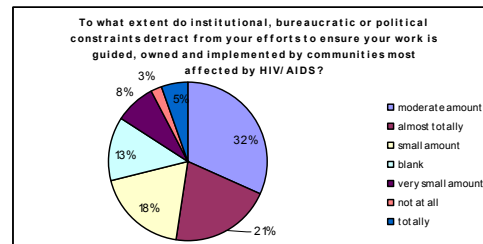
There are strong institutional reasons for this. With levels of spending on HIV/AIDS increasing year on year, donor personnel are under intense pressure to keep transaction costs down, and to prove maximum impact of the funds they spend. Institutional constraints generally require relatively short project funding cycles. Projects with concrete deliverables, like posters, leaflets or high-profile events, are invariably favoured. As those within the donor community are testifying – for example in the forthcoming Panos report – these constraints are becoming more intense, not less.



In-country, small scale partners are often used to funnel resources, although their capacity to do this while also remaining

accountable and responsive to the local community maybe questionable.

In the Panos survey, donors were asked about the extent to which institutional, bureaucratic or political constraints detracted from their efforts to ensure their work was guided, owned and implemented by communities most affected by HIV/AIDS. The majority reported that there was a real issue here, with 21.6% of all donors reporting that institutional factors *almost totally* prevented the work from being guided, owned and implemented by communities most affected by HIV/AIDS, with a further 5.4% saying that these factors completely precluded ownership by those most affected. Remarkably, only 2.7% of donors feel that these factors do not come into play.



Of the 37 donors that responded to the Panos survey only 21.6 percent consult with groups vulnerable to, or affected by, HIV/AIDS.

Contemporary thinking

This would matter less if there was a high level of confidence in existing HIV/AIDS prevention and communication strategies. The fact is, there is not. The new urgency with which AIDS is being addressed by the international community has been accompanied by a re-examination of the effectiveness of existing HIV/AIDS prevention programmes. In particular, approaches focusing solely on changing the behaviour of individuals are being questioned. Instead, the emphasis is moving towards empowering communities and societies to tackle the underlying issues of discrimination, poverty and gender inequality that drive the epidemic.

Two particular developments stand out. Firstly, a major re-examination of communications programming by UNAIDS, which involved consultations in all regions

around the world and culminated in the publication of *A Communications Framework for HIV/AIDS: A New Direction* in late 1999. Secondly, 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 Johns Hopkins University (USA) and Soul City (South Africa).

This UNAIDS framework stated that most HIV Communication programmes were shaped around theories and models that did not meet regional or local needs.

The assumption that knowledge equates to behaviour was also brought into question. The consultations found that where decisions were made by donors or agencies external to the target community, they were often based on inappropriate criteria. It was also noted that there is often an assumption that sex is subject to rational thinking rather than more true-to-life emotional responses.

The consultation found that programmes are often based on strategies designed to trigger a once-in-a-lifetime behaviour, such as immunization. However, HIV/AIDS prevention involves long-term changes in attitudes, life-style and sexual behaviour, together with broader social transformations that might facilitate this change. The consultation found that many prevention efforts had targeted women or focused on condom promotion rather than taking more holistic approaches to reducing sexual risk.

The UNAIDS framework calls for refocusing communication interventions on the basis of five key contextual domains: government policy; socio-economic status; culture; gender relations, and spirituality.

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 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.

These ideas and principles are increasingly influencing donor and international HIV/AIDS thinking. Fewer major organisations now talk only in terms of achieving behaviour change. Increasing numbers talk of using communication to achieve social change. Organisations including USAID, DFID, Unicef and a consortium of Nordic countries now have policies or strategies that emphasise the social change communication approach. These processes, together with others such as the Roundtable, suggest an evolving consensus that previous behaviour strategies have been at best insufficient and at worst have undermined indigenous responses to the epidemic.

However, placing a strategic priority on implementing social change communication strategies is very different from actually implementing them. So far the principles of social change communication have found little purchase in the reality of the ongoing cycles of calls for applications and donor funding. Arguably the increase in funding combined with the urgency of the response (characterised by the pressure to treat HIV/AIDS as an emergency) is leading to an intensification of strategies characterised by the relatively short term, donor driven, behavioural change approaches mentioned above.

<p>Knowledge and Behaviour</p> <p>Surveys show that well over 90 percent of people in the worst affected countries are aware of the disease. Demographic and health surveys from across Africa show levels of HIV awareness and knowledge that correlate only loosely with behaviour or perceptions of risk. It has become increasingly clear that while awareness is an essential prerequisite for changing</p>

behaviour, it is not enough in itself.

Only six percent of all respondents to the Panos survey said that the biggest single obstacle to an effective response to the pandemic was lack of information. By far the largest proportion of people answering the survey (21 percent) perceived lack of political will to be the single biggest obstacle, with lack of funding in second position. 36 per cent quote the various obstacles that relate to deeper-rooted cultural and social issues such as stigma, denial, gender, and social values.

This is not an argument for scaling down information or education activities, particularly as these are one way of addressing political and socio-cultural issues. However, it may well be an argument for revisiting the roles of information and education in light of the key challenges posed within the policy, economic and socio-cultural domains.

Recommendations

Recommendation One: Tackling the donor environment

Donors and large international organisations face major challenges in developing strategies that take a more long-term, process-oriented, indigenously owned approach. They need to find mechanisms that can support such strategies. The advantages of behaviour change communications in funding terms are clear – they allow the expenditure of large sums of money in discrete projects with low transaction costs and quantitative deliverables. Social change communication requires long time horizons, offers fewer concrete deliverables, and presents challenges for evaluation. There are few examples where social change communication has been mainstreamed in large institutions.

The challenges are considerable, but if they are not faced, the danger is that the unique opportunity presented by the current energy and focus on HIV/AIDS will be dissipated in a series of short-term, eye-catching initiatives that further marginalise in-country responses, neglect the clear lessons of the

epidemic to date – and have very little lasting impact.

Such changes will not occur purely as a result of discussions and decisions within the offices of governmental, multilateral or private funders. The media and civil society also play an important role. The institutional pressures creating today's unfavourable donor environment need to be actively identified and addressed by a full range of actors, both North and South. Panos, along with a host of other organisations, will be supporting this process.

Recommendation two: Ownership is the key

Strategies that stress the importance of ownership and participation are the key components of a new direction; one that allows local community agendas to surface above frameworks and institutional priorities imposed from the North. Programming of this kind may take the form of localised faith-based initiatives, or high-profile campaigns such as the hugely successful Treatment Access Campaign in South Africa.

Activities that stress the centrality of an external "change agent", or an information source that emerges from outside the community, need to be closely scrutinised in terms of the degree to which they empower or disempower local leaders and civil society groups. Programmes that work within existing social networks, supporting internally driven responses, although possibly more complex and time consuming, deserve more recognition and assistance.

Similarly, more programmes are required that actively engage with the media and communication environment. Open dialogue and debate at a community, media and policy level is crucial for locally owned, locally driven responses to HIV/AIDS to flourish. These programmes too may have less obvious impacts. Their impacts will relate more to catalysing processes, rather than concrete "deliverables".

Where the ownership of a country or community in an HIV Communication activity is not sought, there needs to be a clear explanation why this is the case.

Conclusion

Where there has been local ownership and local drive in responding to AIDS, impressive results have followed. This lesson appears self-evident. But we have seen that donors and large international agencies face two opposing forces – one for supporting complex, indigenous and long-term responses, and one for spending money fast in a way that can demonstrate clear, if unattainable, results.

Donor funding to tackle this epidemic *is* critical - and still insufficient. The achievements of making HIV/AIDS such an urgent international policy priority are immense and largely due to the efforts of international and donor organisations. However, the overall message of the Roundtable – and also more recently at the 14th International Barcelona HIV/AIDS Conference – was to stress the need to pause and take stock of the current situation and incorporate lessons learnt before deciding how best to turn today's policy and donor climates to the benefit of those most affected by the epidemic.

This need not be a lengthy process; the information is already available. Furthermore, the signals coming from these processes are unambiguous – we need to mainstream a variety of complementary approaches, not only those promoting skills and knowledge for individuals, but also those which address the social, cultural, political and gender aspects of AIDS. Above all, these approaches must respond to the long-term needs of those most affected by the epidemic, rather than the short-term goals of those who draft and fund them.

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277 people responded to our survey online and a further 93 filled in a paper version at the Panos booth at the Barcelona AIDS Conference. Most of the analysis in this report is based on the evaluation of our online survey. 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* (HIVAIDS support networks, AIDS activists or Community based organisations); *donors* (UN agencies, corporate funders, government funders or foundations). *media* or *other* (those that do not fall into any of the above categories).

Survey conducted by Johanna Hanefield

The Panos Survey

The survey that Panos developed was designed as a quick and simple gauge of individuals' perceptions of their organisations' activities and priorities. Although the data the survey generates does not serve as a "stand-alone" authoritative overview, when taken alongside other information sources it illuminates a number of important issues.