

We are one but we are many

New thinking on how communication can support HIV social movements to achieve inclusive social change

'My health situation worsened and I started suspecting that I had AIDS. I got courage and on the 4th of April 1999 I again went for an HIV test at the AIDS Information Centre (AIC). Despite the fact that I highly suspected my partner to be HIV positive, I nearly "went mad" when the counsellor gave me my positive results. I remember telling her something like "Oh God, now my children... they are... anyway they are lovely!" Then immediately I lost sight as tears clouded my eyes. I re-collected myself and I went directly to TASO Mulago Counselling Centre. That day I felt like not wanting to go back home so I stuck around. In the meantime I heard some music from a nearby building and that was the drama group of TASO Mulago.'

The writer is a person living with AIDS wishing to share his experience of living with the disease after testing HIV positive in July 1999. He is now a member of The AIDS Support Organisation (TASO) in Uganda.¹



Live and let live: young people setting the agenda on World AIDS Day in Nairobi
SVEN TORFINN/PANOS PICTURES

Social movements have been identified as powerful forces for inclusive social change in local, national and international responses to HIV and AIDS. They have generated spaces where people can come together for mutual support and to raise awareness about an issue affecting their lives.

Current thinking on HIV communication and social change focuses on promoting interpersonal dialogue and debate. We want to look beyond debate and explore how the processes of communication motivate people to act.

- **How do social movements influence social change?**
- **How do social movements ignite passion and commitment to action?**
- **How does dialogue generate action that contributes to social change?**
- **What is the role of communication and media in helping social movements achieve their objectives?**

We are one but we are many

In this paper, we explore the theoretical foundations for a new Panos project by weaving together recent research about social movements, public debate and communication. We make the case for analysing social movements within communication and social change frameworks.

If you are part of an HIV social movement, a politician or government official, part of a civil society organisation, a person living with HIV or someone simply interested in this topic, we want to hear from you about how your experiences compare with the ideas put forward in this paper. Please contact: hivaid@panos.org.uk

¹ www.tasouganda.org/testimonies.php

Social movements and social change

'Social movements are communication dependent; in their very essence and being they are communication processes... So – if these social movements have been communication-based and have had an impact, then what can we learn from them for our development communication strategies and efforts?'

Warren Feek 2005²

An AIDS activist takes a break from campaigning to make antiretroviral treatment available to all in South Africa.

PEP BONET/PANOS PICTURES



Social movements tend to be formed by organic, ad-hoc and unpredictable processes. The movements also tend to go through a lifecycle formalising them into an organisation that can receive grants and be visible to a national and increasingly international audience. Communication is critical in every stage of this evolution – spanning the moment someone first articulates their passions and connects with others, to the exchange of ideas between members of a group, to advocacy and activism around these issues with a wider audience. Communication is central in sustaining the social movement itself, as well as in shaping how the movement influences social change.

Before looking at communication, we must take a step back and first consider social movements in processes of social

change. This is a complicated relationship, and can be unpacked by looking at it from three different angles: social movements themselves as processes of collective action; the relationship between the social movement, the state and social policies; and individuals within social movements and their motivation for getting involved.

Social movements as processes of collective action

Social movements and their scope of influence form only a small part of wider processes of social change. Significantly, social movements have often been seen as a weapon of the weak against the strong (although this is not always the case as some movements are led by elites). In terms of development theory, social movements have enabled people at the periphery of economic and social decision-making processes to create new centres of power and challenge previously closed spaces of decision-making.³ A good example of this is the rise of indigenous peoples' movements, which have been particularly strong in Latin America.

The relationship between the social movement, the state and social policies

In looking at the influence of social movements on political decisions and social change, we must also look at the responses of governments to social movements, and how they work with them. In this sense, social movements can be seen as part of wider civil society engagement with government, and this relationship is continually being redefined through conflict and negotiation.⁴

'Policy makers influence the world, but who influences policy makers?'

Elaine Murphy 2005⁵

In South Africa for example, history and social context shape the relationship between social movements and the government. If we compare the anti-apartheid movement with the Treatment Action Campaign (TAC), the importance of this relationship becomes obvious. Where TAC was able to influence the government of South Africa to develop an antiretroviral treatment plan after four years of advocacy, Nelson Mandela spent 27 years in prison as part of an ongoing struggle to end apartheid and promote social equality. TAC works within a multi-party democratic state, advocating for specific policy change.

² The Drum Beat, Issue 307: Social Movement Communication. www.comminit.com/drum_beat_307.html

³ TK Oomen, 2004, *Nation, Civil Society and Social Movements: Essays in political sociology*, London: Sage.

⁴ P Houtzager, 2003, 'Introduction: From polycentrism to the polity', in P Houtzager and M Moore (eds), *Changing Paths*, Michigan: University of Michigan Press.

⁵ Murphy, Elaine M, 2005. 'Promoting healthy behavior', *Health Bulletin*, Number 2, Population Reference Bureau, p.14.

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P Freire, 1970, *Pedagogy of the Oppressed*, London: Penguin 1996.

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See also S Tarrow, 1998, *Power in Movement: Social Movements and Contentious Politics*, Cambridge Studies in Comparative Politics, Cambridge: Cambridge University Press.

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S Robins, 2005, *Rights passages from 'near death' to 'new life': AIDS activism and treatment testimonies in South Africa*, IDS Working Paper 251, Brighton: Institute of Development Studies.

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J Foweraker, 1995, *Theorizing social movements*, London: Pluto Press.

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D Della Porta and M Diani, 1999, *Social movements: An introduction*, Oxford: Blackwell Publishing.

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W Feek, 2003, *The Power of Movement*, the Communication Initiative: ConnunDRUMS, www.comminit.com/conundrums/conundrums/conundrums-7.html

The anti-apartheid movement on the other hand was operating within a one-party, repressive state, advocating for complete political reform. Many factors were involved in each case which we do not have the space to go into here, such as the changing dimensions of global activism, foreign connections, legal frameworks and spaces for participation. This quick comparison does however highlight that the nature of government and political context also determines the effectiveness of social movements in influencing change at the political level.

'It is only the oppressed who, by freeing themselves, can free their oppressors.'

Paolo Freire 1970⁶

Individuals within social movements and their motivation for getting involved

Social movements are not homogenous entities, and are profoundly shaped by the identities of their members. This is just

as true for HIV social movements as for others in recent times, such as the women's, anti-globalisation, peace and indigenous peoples' movements. Their members' identities and characteristics are as complex and diverse as those of their leaders. Understanding why people participate in social movements and how that participation shapes their identity is critical for understanding the passions and motivations that sustain them.

It is these dimensions of identity and of origin in grassroots networks that make social movements unique.⁷ Because social movements are often formed by marginalised people, coming together around a common issue, they can provide mutual support and a sense of solidarity. For people living with HIV and AIDS, this support can help to shape a positive meaning to a positive diagnosis.⁸ It is also the intensity of this personal engagement and the collective identity it generates that can enhance the sustainability of the movement.

What are social movements?

Social movements are notoriously difficult to define, particularly because of the intensely contextual nature of how they function. The theorists converge around the idea of a social movement as a process – that is, a definition based on the processes of engagement in social change, not solely on a group of people coming together.⁹ As such, social movements can loosely be defined as interactive networks of people who have shared beliefs and a sense of solidarity, and who come together to take part in collective action to challenge the status quo.¹⁰

What is inclusive social change?

Social change is a complex process that can be as specific as changes in behaviour in one individual and his or her environment, or as all-encompassing as political reform or national policy. Social change is heavily influenced by the interpersonal, historical, geographical and political context in which it occurs. This 'change' is inclusive when the process is influenced, and ideally driven, by the people who are most affected. It is the people most affected, not policy-makers, who really understand the complexities of the impact HIV has on everyday life.

Although this paper focuses on positive and progressive examples of HIV social movements, it is recognised that social mobilisation can also lead to discriminatory or negative social change. The recent anti-immunisation campaign in northern Nigeria is one example of how a health-related social movement, based on misinformation, is influencing personal and social change that is in fact detrimental to public health.¹¹ Arguably the people involved in the movement are mobilising around a cause that they believe to be about social justice and what they perceive to be the greater public good.

What is communication for social change?

Communication for social change puts people at the centre of their own change, setting their own priorities, finding their own ways of communicating and organising. Communication for social change is a framework for understanding how dialogue between people can support them in making informed and relevant decisions about how to live their lives. HIV has implications for everything we think of as 'development' – from rights to sexuality, from inequality to livelihoods, to donor funding mechanisms – and it has led to multiple innovations in communication. Each innovation has created an opportunity to learn from successes and failures, and deepen an understanding of how communication can help or hinder responses to HIV.

Within each of these processes – social movements, social change and communication – there are complex relationships of power, representation and identity. Each process has inherent opportunities and risks – opportunities to generate positive change if the process is inclusive, legitimate and democratic; but these opportunities are also at risk of abuse, corruption and compromise.

Spaces for debate

Recent research has focused on spaces of public engagement as a means of understanding dimensions of decision-making, and the influence of individual citizens and civil society on these decisions. Researchers have distinguished between closed, invited and claimed spaces for public debate; the explicit, hidden and invisible power relationships operating within each; and the local, national and global venues in which these debates occur.¹² Building on these characteristics, Hope Chigudu, a Zimbabwean activist, further differentiates between claimed and autonomous spaces: claimed spaces are those in which people claim entry to institutions where they should be included (but haven't been invited); autonomous spaces are those outside the structures of the state where people mobilise for themselves and develop their confidence, skills, solidarity and strength towards achieving their objectives.¹³ While social movements are present and active in each of these spaces, it is their participation in and creation of autonomous spaces that makes them unique and powerful compared with more institutionalised forms of social activism.

This focus on space and dynamics of power is equally important within social movements as well as in spaces of public debate. It serves as a useful tool for analysing both the processes of communication within social movements (and questions of representation and legitimacy) as well as the process by which the movement engages in public debate. It allows us to focus on the relations of

power and constructions of identity that underlie all aspects of public engagement.¹⁴ Examples of these different spaces in the context of HIV social movements could include those shown in the table below.

Within each of these spaces, complex power dynamics and interpersonal communication are running in parallel with processes of collective advocacy and external communication. For example, in the 'invited space' might be the leader or spokesperson of a social movement, advocating on behalf of 10,000 members, to members of the National AIDS Council. In itself, this example raises important questions about the internal communication processes of the social movement, touching on dimensions of legitimacy, voice and accountability:

- **Who speaks on behalf of whom?**
- **Whose voices are the loudest?**
- **Whose perspectives are the most influential in shaping the agenda of the social movement as a whole?**

Likewise, the example raises important questions about the external communication of the social movement:

- **How are the priorities of the social movement presented?**
- **If the social movement has worked with the media, on whose terms and how legitimately have the objectives been represented?**
- **How effectively have the messages been targeted to and influenced the intended audience?**

¹² J Gaventa, 2002, *The uses of power in framing and shaping the spaces, places and dynamics of participation*, A discussion note for the IDS Citizenship Development Research Centre, 22 October 2002.

¹³ Thanks to Andrea Cornwall for sharing this useful distinction.

¹⁴ A Cornwall, 2003, *New Democratic Spaces? The politics and dynamics of institutionalised participation*, IDS Bulletin 35:2.

Space of debate for HIV social movements		
	Internal	External
Closed space	Meeting of the executive committee (or equivalent)	G8 policy roundtable discussion between national leaders, such as that held in Edinburgh 2005
Invited space	Opportunities for member involvement in shaping objectives, electing a chairperson, revising the constitution	Opportunities for civil society monitoring and input to the UNGASS (UN General Assembly Special Session on HIV/AIDS) review process in 2006
Claimed space	Members calling a meeting to challenge a decision by the organising committee	Demanding seats for representatives of social movements to be included in the civil society UNGASS review meeting
Autonomous space	Support group meetings organised and convened by the members	World AIDS Day marches like those that occurred in Maseru (Lesotho), Agartala (India) and Moscow (Russia) on 1 December 2005



HIV-positive women making handicrafts in their support group. The group's name is *Abatanyuranya* which loosely translates as 'those that bond together'.

STUART FREEDMAN/PANOS PICTURES

In the context of the HIV epidemic, communication was initially seen purely in terms of information dissemination to educate people about HIV, and about HIV prevention in particular. This included things like public service alerts that outlined the biological information about the disease, how it is transmitted, and how to prevent infection. The media was ascribed a key role, primarily focused on a one-to-many dissemination of information model.¹⁵ This vertical, top-down approach tended to focus on the individual without recognition of context and was based on the false assumption that behaviour is a product of rational decision-making processes.

'Too often communication was mistakenly conceived as propaganda or, in the best scenario, as information dissemination, but seldom seen as dialogue.'

Alfonso Gumucio Dagron 2001¹⁶

Moving on from the mistakes of the early days, communication approaches shifted to include these information dissemination models as part of a more holistic response and looked at interpersonal levels of communication. A more holistic communication response looks at horizontal communication between groups of people as well as the reverse vertical mode of communication – that is, from the bottom-up, one-way messaging from people most affected to policy-makers.¹⁷ One example of this type of communication approach is the LoveLife programme in South Africa that uses a mix of peer-based communication initiatives (youth clubs, radio call-ins and peer education groups) with top-down (billboards, advertisements and leaflets) and bottom-up (petitions and billboard design competitions) communication approaches.¹⁸

It is now time to move on again. Social movements and their role in influencing social change challenge us to look at how communication transforms debate into action – how it mobilises communities, ignites passions and fosters linkages between people. We need to question and understand how communication can best be utilised to amplify the voices of people most affected and to support social movements.

The International Community of Women (ICW) is an international movement bringing together women affected by HIV and AIDS around the world. It is the only international network run for and by HIV-positive women, and was formed by a group of HIV-positive women from many different countries who stormed the platform of the 8th International Conference on AIDS held in Amsterdam in July 1992. Nowadays, much of ICW's work is less visible but no less powerful behind-the-scenes activism through lobbying, so that change can happen without confrontation. This approach reflects the reality that many women still can't be open about their status, that not every woman can afford the time to go to demonstrations – or to risk being photographed by the press, arrested or injured at them – or to write to email groups, since women often have many other commitments as carers of family and friends.

Communication for social change – raising informed public debate

Spaces of public engagement can therefore provide a useful lens through which to analyse communication processes within social movements. Because social change and indeed personal change is a nuanced and complicated process, it is difficult to demonstrate a causal influence of one contributing factor, such as communication, on that process. In this paper and the Panos project overall, social movements and social change will be examined through the lens of communication, while recognising the many other factors influencing both.

¹⁵ Panos, 2003, *Missing the Message? 20 years of learning from HIV/AIDS*, London: Panos.

¹⁶ AG Dagron, 2001, *Making Waves: Stories of Participatory Communication for Social Change*, New York: The Rockefeller Foundation, p. 9.

¹⁷ G Bessette, 1996, 'Participatory Development Communication-Development in West and Central Africa: toward a research and intervention agenda', Canada: International Development Research Centre.

¹⁸ www.lovelife.org.za

How can communication and media best support social movements?

Communication processes are critical within a social movement in influencing and setting agendas, as well as externally for the social movement engaging with decision-makers.

In 2003 Panos published a report critically analysing the role of communication in global responses to HIV. *Missing the Message* concluded, among other things, that greater efforts were needed to prove the impact of empowering communication methodologies – that is, communication approaches that look beyond the individual to promote locally relevant, informed and inclusive interpersonal debates and sustained changes in attitudes and behaviour. Two of the concerns highlighted by the report were the role of the media, and the role of participatory communication. These two areas relate directly to the external and internal communication processes associated with social movements, and provide a useful frame for advancing thinking about how communication can effectively support social movements in combating the HIV epidemic.

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J Deane, N Mue and F Banda, 2002, *Global Civil Society*, Oxford: Oxford University Press, p. 171.

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Panos, 2003.

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G Bessette, 1996.

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M Heywood, 2004, *Price of Denial*, www.tac.org.za

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S Robins and B von Lieres, 2003, *AIDS Activism and globalisation from below: Occupying new spaces of citizenship in post-apartheid South Africa*, *IDS Bulletin* 35:2.

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H Wasserman, 2005, 'Renaissance and Resistance: Using ICTs for Social Change in Africa', *African Studies* 64:2.

AIDS awareness posters provide a talking point for sex workers in an information centre in Ethiopia. PEP BONET/PANOS PICTURES



The role of media in promoting informed and inclusive public debate

In order for the media to be active and influential in shaping inclusive social change, it needs to be independent, locally relevant, and taken seriously by audiences spanning from the most powerful government officials and policy-makers to citizens on the street. When this is the case, the media can be a powerful and effective mechanism for holding decision-makers to account, generating informed and critical public debate, and amplifying the voices of people most affected.

'Freedom and pluralism of the media are both a product and an engine for an inclusive, genuinely civil society.'

James Deane, Njonjo Mue and Fackson Banda 2002¹⁹

In this way the media, with its potential ability to reach audiences spanning very different lifestyles and contexts, has an enormous opportunity to influence responses to HIV. Beyond opportunity however is an accompanying responsibility to report in a way that promotes positive social change and inclusion rather than perpetuating the stigmatisation and exclusion of those most affected by HIV and AIDS.²⁰ For social movements, engagement with the media can be a powerful advocacy tool, a way to reach new members and raise the profile of the movement.

In addition to large-scale mass media, small-scale grassroots and traditional methods of communication have also evolved within responses to the HIV epidemic.²¹ These include posters, videos, slide-shows, word of mouth, and theatre. New media and alternative publications have also been identified as useful forms of communication within social movements, although they highlight the difficulties of accessing new technologies in resource-poor settings. Examples of new media include emails, websites, email newsletters, and text messages from mobile phones. Alternative media refers to magazines or other publications that are produced outside mainstream media houses by people who are not necessarily media professionals. There are implications for social movements, where differences in access to new technologies can exacerbate inequalities in visibility between members in urban and rural areas, between men and women with different responsibilities and information and communication technology (ICT) literacies, and between the leaders and members of a social movement.

The Treatment Action Campaign (TAC) in South Africa has used a variety of different media technologies (web, photo, video and written narratives) to document personal testimonies from the diverse members of the network as well as that of Zackie Achmat.²² One key aspect of the success of TAC in advocating for access for all to treatment and care in South Africa (which resulted in a national policy change in 2003) is the breadth and diversity of its membership and its highly visible and effective public image.²³ Recent research has looked at the role of new media and TAC, and argues that alternative media can complement as well as supplement 'traditional' media. For example, TAC uses text messages as well as word of mouth to mobilise crowds at their demonstrations, and publishes alternative news bulletins as well as press releases about its activities.²⁴

The evolution of new technologies and alternative media raise key questions about media and social movements:

- **How do new and alternative media redefine or create new spaces for public debate?**
- **How do new and alternative media challenge concepts of social movements, if they allow people to find support and solidarity through virtual networks that may not necessarily include collective action?**
- **How do new technologies enhance or hinder processes of legitimate representation within the social movement?**

In terms of social movements and processes of social change, we must look beyond traditional forms of mass media at how alternative media influence, and are utilised by, social movements.



Listen to the small voices: gay pride marchers in Kathmandu celebrate the identities of transvestites, transexuals and men who have sex with men.

PIERS BENATAR/PANOS PICTURES

The role of participatory communication in promoting informed and inclusive public debate

Participatory communication processes are where people most affected are talking directly to each other or to their peers, rather than being talked about by a third party (such as in the media). This includes the activist shouting through a megaphone at a treatment demonstration rally; the sex worker giving a condom demonstration in front of her peers; and the college student involved in a stop AIDS campaign. All these people, and many more, are some of the individuals with distinct voices, identities and circumstances that are communicating about HIV and AIDS in their own realities. As such, participatory communication happens organically, where spaces and opportunities are available or claimed.

Just as with spaces of debate, participatory processes are imbued with explicit, hidden and invisible power relations.²⁵ As indicated above, much rests on the critical self-awareness

of those involved in ensuring that the process is inclusive, empowering and non-stigmatising.

Because social movements gain their strength from the passions and commitment of the people involved, the processes of communication between these people are critical in how the movement influences social change. It is exactly because participatory communication and social movements are processes rather than outcomes or objectives that we need to look at 'how' as well as 'what' they are striving to achieve. Participatory communication therefore is central for supporting and connecting the identities and passions that sustain social movements.

From debate to action: how can communication and media support HIV social movements to influence inclusive social change?

'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.'

Panos 2003²⁶

Given the shortcomings of communication in the past to be effective in local, national and international responses to HIV and AIDS, we urgently need to scrutinise and answer this critical question: how can communication more effectively support people most affected by HIV and AIDS to debate, act and bring about change in the struggle against the ever-increasing spread of the HIV epidemic?

In 2006 Panos London is undertaking a pilot phase for the social movements project. The project will work with partners in the UK, South Africa, Brazil and Nepal. It aims to strengthen how these social movements contribute to social change by understanding how communication takes place within them, how effective communication can be replicated, how relationships with the media can be enhanced, and how social movements can share knowledge and learn from each other. We will work with a variety of participatory techniques, including collecting life histories, participatory video and photographs. The project aims to support advocacy and the amplification of the objectives of the HIV social movements as well as the individual voices within them.

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U Kothari, 2001, 'Power, Knowledge and Social Control in Participatory Development', in B Cooke and U Kothari (eds), *Participation: The New Tyranny*, London: Zed Books.

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Panos, 2003.

'We want to achieve effective long-lasting policy change and make sure it is properly funded, to provide treatment access and prevention policies which genuinely and humanely address the root causes of this pandemic... We want to ensure that the voices of HIV-positive women ourselves, who have learnt most about the failure of existing messages, are supported to form a central part of an effective response.'

Alice Welbourn 2005²⁷

It is ultimately the lived experiences and priorities of people most affected by HIV and AIDS that can best inform and indeed steer effective responses to the epidemic. Yet to date this is still not the case. The challenge therefore is to think creatively and critically about how communication can best support inclusive social change.

Debate and dialogue alone are not enough, regardless of how informed, inclusive and progressive they may be. As we have indicated here, more attention needs to be paid to the powerful role of social movements in stimulating social change, providing mutual support, and capitalising on the individual passions and motivations that sustain them. We must also recognise the intrinsic role of communication in supporting social movements to advocate effectively.

This paper has positioned social movements within current thinking about communication and social change. In doing so, it challenges us to look more critically and creatively at how communication can be more effective in fighting HIV and AIDS.

- **How does communication support the transition from debate to action?**
- **What is the role of communication in mobilising communities, igniting passions and supporting social movements?**
- **How does communication translate debate into action that ultimately leads to change?**

Please contact the Panos London AIDS Programme with your thoughts, feedback and suggestions on these important issues: hiv aids@panos.org.uk

²⁷ Speech at the launch of SOFIA (<http://www.sofiaforum.org>), House of Commons, London, 23 November 2005.

Other useful resources

- Panos Global AIDS Programme: www.panos aids.org
- The Communication Initiative: www.comminit.com
- Communication for Social Change Consortium: www.communicationforsocialchange.org/index.php
- Treatment Action Campaign, South Africa: www.tac.org.za
- International Community of Women Living with HIV: www.icw.org
- The AIDS Support Organisation, Uganda: www.tasouganda.org
- World AIDS Campaign: www.worldaidscampaign.info/index.php/wac/wac
- International Treatment Preparedness Coalition (ITPC): www.globaltreatmentaccess.org/content/tx_prep/
- Global Network of People Living with HIV/ AIDS (GNP+): www.gnpplus.net/cms/index.php
- Asia Pacific Network of People Living with HIV/AIDS (APN+): www.apnplus.org/home/index1.html
- Solidarity & Action Against The HIV Infection in India (SAATHII): www.saathii.org/index.html

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Panos London is part of a worldwide network of independent NGOs working with the media to stimulate debate on global development issues.

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Designed by John F McGill

For further information contact:

HIV/AIDS Programme
Panos London
9 White Lion Street
London N1 9PD
UK

Tel: +44 (0)20 7278 1111
Fax: +44 (0)20 7278 0345
www.panos.org.uk
hiv aids@panos.org.uk
www.panos.org.uk/aids