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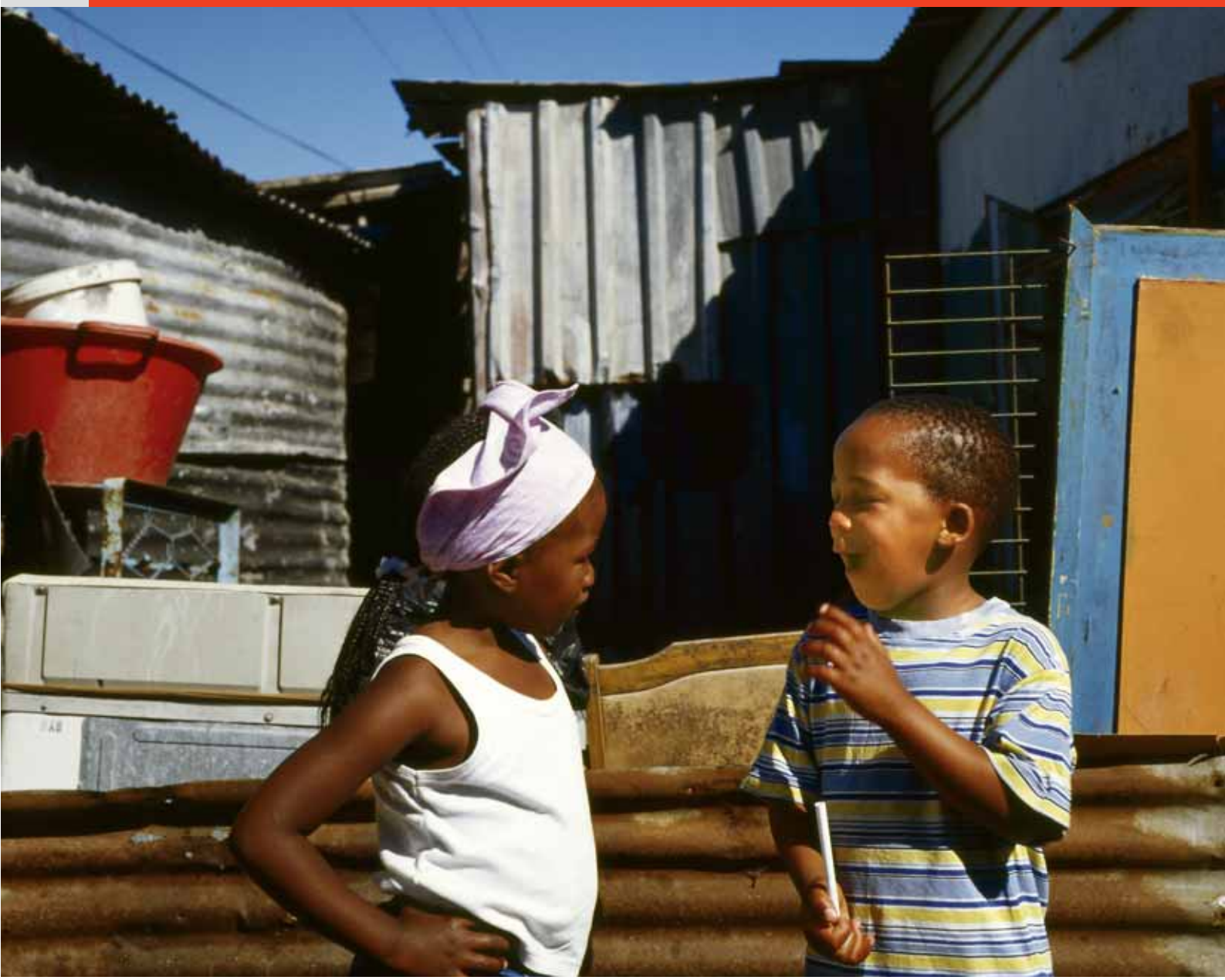

Breaking barriers

Effective communication for universal access to HIV prevention, treatment, care and support by 2010

GLOBAL AIDS PROGRAMME

www.panosaids.org

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Universal access to HIV prevention, treatment, care and support by 2010 is a goal with a rapidly approaching deadline. Effective communication of all kinds and between all those involved is absolutely vital if universal access is to become a reality.
PEP BONET | PANOS PICTURES

The **Panos Global AIDS Programme** is a network of Panos offices in Africa, Asia, the Caribbean and Europe, working on participation, ownership and accountability in the fight against HIV/AIDS.

Panos exists to stimulate debate on global development issues. Panos provides in-depth information on the social and economic causes and consequences of the HIV/AIDS epidemic in the developing world. In addition, Panos plays a key role in the development of contemporary approaches to HIV/AIDS communication.

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Abbreviations and acronyms

ARV	antiretroviral
ART	antiretroviral treatment
CFSC	Communication for Social Change
GIPA	greater involvement of people living with HIV and AIDS
MIPA	meaningful involvement of people living with HIV and AIDS
NGO	non-governmental organisation
PLWHA	people living with HIV and AIDS
TAC	Treatment Action Campaign
TRIPS	trade-related aspects of intellectual property rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	voluntary counselling and testing
WHO	World Health Organization
WTO	World Trade Organization
UNESCO	United Nations Educational, Scientific and Cultural Organization

Introduction

In 2005, twenty-five years after AIDS was first recognised, G8 governments, the African Union and the UN World Summit called for 'as close as possible to' universal access to HIV prevention, treatment, care and support by 2010. This call was endorsed by African heads of state in Abuja, Nigeria in early 2006, and the high-level meeting of the UN General Assembly in June 2006.

In 126 country consultations during 2005 and 2006,[1] UNAIDS identified the following key elements towards scaling up universal access:

- the need to build on existing processes at all levels
- country-driven processes and targets, supported by international and bilateral institutions and donors, harmonised through the Three Ones principles (see page 16)
- a comprehensive and integrated HIV and AIDS response that includes prevention, treatment and care
- participation of a wide range of stakeholders – especially civil society and people living with HIV and AIDS (PLWHA).

The country consultations also identified the following obstacles to scaling-up. Practical solutions must be found to overcome:

- stigma and discrimination against PLWHA and the most at-risk groups
- inequality faced by women and girls
- funding shortfalls and the lack of predictable and sustainable financing of the HIV and AIDS response
- weak health systems, shortages of health personnel and the lack of affordable medicines, diagnostics and prevention commodities.

Effective HIV and AIDS communication is central to the achievement of universal access. This paper reviews lessons learned from the response so far and suggests that there is an urgent need to strengthen communication approaches that look beyond narrow, short-term interventions focused on individual behaviours. Development actors must realistically and effectively engage the social, political and economic drivers of the epidemic, in a way that is informed by the experiences and priorities of those most affected. There is also a need to better understand and engage with the distinct communication dynamics of social movements and the neglected area of interpersonal communication – both of which are key to an effective response. The intransigent problems of stigma and discrimination must also be addressed. The challenge is at once social, political and technical, but without this paradigm shift in development and communication practice, universal access will remain elusive.

As country-level plans for universal access are being developed in late 2006, it is vital that they explicitly include fully resourced communication strategies, activities and targets that are integrated into programming at all levels. Communication challenges include: the effective coordination of the response; sustained advocacy to tackle the underlying drivers of the epidemic; and the specific communication needs of prevention, treatment and care initiatives that require grassroots ownership and social mobilisation.

1 UNAIDS (2006), *Scaling up access to HIV prevention, treatment, care and support: the next steps*, Geneva: UNAIDS

Lessons from the response to HIV and AIDS 1

Community organisations have played a large part in successful responses to HIV and AIDS in many countries.
HELDUR NETOCNY | PANOS PICTURES

A number of factors, present to varying degrees in different countries, have been prominent in successful responses to HIV and AIDS, and have been reviewed elsewhere in detail.[2] Factors which contribute to a successful response include:

- **political leadership:** played a major role in tackling the epidemic in Uganda, Thailand, Senegal and Brazil
- **civil society mobilisation:** the combined actions of non-governmental organisations (NGOs), women's groups, communities, faith-based organisations and others underpinned successful wide-scale social responses in Senegal and Uganda
- **open dialogue:** in Uganda, discussion and knowledge-sharing in personal communication networks made people feel that HIV and AIDS affected them personally, promoting changes in behaviour
- **the media:** raised awareness and promoted dialogue and debate in Thailand, Brazil and Uganda
- **country-driven responses:** drawing on local expertise, a home-grown set of approaches and priorities were produced by government in partnership with civil society in Senegal, Uganda and Jamaica
- **multisectoral responses to prevention and care:** including multiple government ministries; involving of all levels of society from national to community level
- **matching the response to the stage and character of the epidemic:** combining efforts aimed at the majority population and those focused on high-risk groups
- **targeted large-scale interventions,** combined with a range of prevention approaches
- **effective monitoring** of the epidemic and risk behaviours, and using the findings to support improved policies and programmes.

2 See Sittitrai, W (2001), *HIV prevention needs and success: a tale of three countries*, Geneva: UNAIDS; Panos (2003), *Missing the Message: 20 years of learning from HIV/AIDS*, London: Panos; Green, E (2003), *Rethinking AIDS prevention: learning from successes in developing countries*, Connecticut: Praeger; Singhall, A and Rogers, E M (2003), *Combating AIDS: communication strategies in action*, London: SAGE

Taking stock in 2006, it seems that many of the lessons learned so far are not being applied today. Civil society reviews of country responses, undertaken to monitor implementation of the UNGASS Declaration, found that political commitment and leadership to tackle HIV and AIDS is still lacking in many countries.[3] National responses remain largely donor-driven, raising important questions about ownership and sustainability, and the meaningful involvement of civil society – especially PLWHA – remains minimal. Some countries are still failing to tailor HIV prevention to the type of epidemic being experienced, while countries with low-level and concentrated epidemics need to focus on effective prevention for vulnerable groups. Many countries need stronger monitoring and evaluation systems, which are often donor-focused and under-resourced. We return to some of these challenges later, after briefly reviewing the contribution of communication and some of the new approaches which promise to unlock enduring barriers to effectively tackling HIV and AIDS.

What is communication?

An expanded definition considers communication as **the processes of dialogue, exchange of information and resources, and the capacities that enable understanding, negotiation and decision making around an issue**. Such an understanding of communication includes the technical focus on audiences and media channels for information in development communication programmes. It also brings into view the existing relationships and processes of dialogue in any setting, the resources and capabilities that different groups draw on for communication, and how these support individual and social change.

Communication in development has often been understood in a technical sense to refer to the variety of ways of providing information and 'messages' to people, and the different approaches and media 'channels' for this purpose. Participatory communication suggests a need to go beyond delivering 'messages' to particular groups of people to change their attitudes and behaviour, focusing instead on a two-way process of dialogue and participation, and the broader social context and set of enabling factors and resources that support communication in any setting.

Since communication plays a role in most social processes, it risks being 'everywhere but nowhere', and therefore not dealt with systematically. This has led some communication practitioners to divide the different aspects of communication into: programme communication, advocacy and social mobilisation.[4] Programme communication aims to catalyse individual and social action around an issue, through information, awareness-raising, and activities focused on the general public or particular groups. Advocacy aims to foster political will and resources by placing an issue high on the political or development agenda and holding authorities accountable. Social mobilisation seeks to bring stakeholders together and build both demand and commitment to tackle an issue.

It is also important to recognise that much existing communication goes on outside of formal health and development initiatives: in social movements and cultural responses to HIV and AIDS, for example. Anthropological work has also shown that all aspects of everyday life have communicative dimensions: so beliefs about HIV and AIDS are often expressed unconsciously through daily activities and practices. Development communication programming thus needs to be able to accommodate, and be responsive to, these independent communication dynamics if it is not to amount to persuasion and social engineering.

3 See Panos (2006), *Keeping the Promise? A study of progress made in implementing the UNGASS Declaration of Commitment on HIV/AIDS in seven countries*, London: Panos; OSI (2006), *HIV/AIDS Policy in the United States: monitoring the UNGASS Declaration of Commitment on HIV/AIDS*, New York: Open Society

4 WHO (2006), *Advocacy, communication and social mobilisation to fight TB: a 10 year framework for action*, Geneva: WHO Stop TB ACSM sub group

Strengthening communication approaches that address social complexity 2

Dialogue and discussion are at the heart of effective communication around HIV and AIDS.
MARK HENLEY | PANOS PICTURES

'Believe me you are not to blame, you should not feel ashamed, it is us to blame: we who tolerate ignorance and practice prejudice, we who have taught you to fear. We must break the silence now, making it safe for you to reach out for compassion.'

Asunta Wagura
Kenya Network of Women with AIDS

A wide array of communication interventions have proven effective – from media and social marketing campaigns that raise awareness of HIV and AIDS, to peer education that supports HIV prevention efforts in particular high-risk groups. Communication interventions that promote engagement and dialogue – particularly among peers – have been key for changes in behaviour.[5] The Communication Initiative has gathered a growing body of communication impact data, and the World AIDS Campaign has created a useful compendium of communication methods and tools.[6] A range of participatory communication tools to support community-level work are also available – such as Healthlink Worldwide's *Communication for Advocacy* manual, and its Quest approach for developing appropriate communication campaigns and materials.[7] Various organisations are strengthening evaluation approaches that can address the processes of dialogue, debate and influence in networks of social relationships that are integral to communication.[8]

Despite the successes of development communication, more needs to be done to address the social complexities of HIV and AIDS. The pandemic touches on all aspects of life: sexuality and identity; notions of morality and gender; understandings of disease and death; stigma and discrimination. Communication approaches based on the assumption that individuals make rational choices about their behaviour cannot therefore effectively address the complex social character of HIV and AIDS.

HIV and AIDS have driven innovations in communication that attempt to address their social roots. A rich range of participatory approaches have attempted to take social context more seriously, and recognise the need for a sustained effort to build communication capacity at local levels, so that communities and individuals can lead their own change process, relevant to their local conditions. Such a process is most effective when it promotes both collective discussion and individual reflection and self-awareness. At the same time, rather than begin with externally defined messages, there is a common emphasis on the process of dialogue and negotiation of change at many levels that is firmly grounded in the priorities of people at the front line of tackling HIV and AIDS.

5
Singhall, A and Rogers, E (2003), see footnote 2, chapters 7 and 8

6
World AIDS Campaign communication tools: www.worldaidscampaign.info; The Communication Initiative impact data: www.comminit.com/mdgs/mdgs/mdgs-7.html

7
Healthlink Worldwide (2005), *Communication for Advocacy* training manual, London: Healthlink Worldwide, www.healthlink.org.uk; Healthlink Worldwide (2004), *Quest: participatory communication training manual*, London: Healthlink Worldwide; FAO/SADC (2005), *Participatory Rural Communication Appraisal, starting with the people: a handbook* (2nd edn), Rome: FAO/SADC

8
See Byrne, A *et al* (2005), *Measuring Change: A Guide to Participatory Monitoring and Evaluation of Communication for Social Change*, New Jersey: CFSC Consortium; Healthlink Worldwide (2005), *Evaluating networks key list* www.asksource.info; M and E News Networks section: www.mande.co.uk

The UNAIDS communication framework for HIV and AIDS, developed through global consultation in 1997–9, draws attention to the importance of social context in the response to HIV and AIDS.[9] It rightly criticises the 'methodological individualism' of much health communication in the behaviour change tradition.[10] In responding to HIV and AIDS, several aspects need to be addressed to sustain changes in behaviour: spirituality, gender, socio-economic status, policy frameworks and culture. Despite generating much interest, this framework has yet to lead to sustained programming on the ground. Communication for Social Change[11] (CFSC) similarly recognises the intimate link between individual and social change and the need for people to be at the centre of their own change process. CFSC/UNICEF initiatives in East and Southern Africa, which draw on the human rights-based approach to programming,[12] have begun to put social change communication into practice. Useful evaluation tools have also been developed to address the process and relationship changes that are central to social change.[13]

Communication for social change in practice

In Ethiopia, the CFSC process has worked through a large network of youth clubs in a dialogue and decision-making process that sets the agenda for the HIV and AIDS response. The process stimulated dialogue within existing networks and groups, and amplified the voices and concerns of young people and their communities through a variety of media to stimulate discussion at district and national levels.[14] Linkages with government partners sought to create channels for government and development agencies to respond to the issues raised and improve services and policy. In Ethiopia, CFSC built on the successful 'community conversations' developed by UNDP and UNICEF, which have promoted dialogue around previously taboo subjects such as female genital mutilation, early marriage and sexual violence. Such community conversations have sought to build the capacity of communities to reflect on their own priorities and find their own solutions. They have also creatively addressed religious and traditional practices that may heighten risk of HIV transmission.[15]

In a similar fashion, UNAIDS has facilitated the strengthening of 'AIDS competence' among communities in China's Mekong region, through a community-owned process of self-assessment of strengths and needs in responding to HIV and AIDS, coupled with shared learning between communities.[16] The need for informed and inclusive local-level debate as a basis for engaging in wider social change is also emphasised in more established participatory communication approaches such as REFLECT.[17]

Inevitably, attempts to deal with broader social change face more difficulties than interventions aimed at short-term, relatively narrowly defined change. Although there is growing consensus around the need for communication approaches that attempt to engage with social complexity,[18] they deserve more attention and investment. This will help to develop more flexible programming that builds on inclusive social change where it already exists, rather than trying to direct it from above. More responsive programming would be consistent with rights-based approaches, and promote internally driven change – which is ultimately more sustainable.

9 UNAIDS (1999), *New Communication framework for HIV/AIDS*, Geneva: UNAIDS

10 Airhihenbuwa, C O and Obregon, R (2000), 'A critical assessment of theories/models used in health communication for HIV/AIDS', *Journal of Health Communication* Vol 5 Supplement: 5–15

11 See www.communicationforsocialchange.org

12 Ford, N, Odallo, D and Chorlton, R (2003), 'Communication from a Human Rights Perspective: Responding to the HIV/AIDS Pandemic in Eastern and Southern Africa', *Journal of Health Communication*, Vol 8 No 6

13 Byrne, A *et al* (2005), see footnote 8

14 Byrne, A *et al* (forthcoming), *Youth-focused dialogue about HIV/AIDS in Ethiopia: using and evaluating communication for social change*. New Jersey: CFSC Consortium

15 See UNDP, *Upscaling community conversations*: www.et.undp.org/hiv/CC.htm

16 UNAIDS/UNITAR (2005), *Evaluation of the UNAIDS/UNITAR AIDS Competence Programme*, Geneva: UNAIDS

17 For more information see www.reflect-action.org

18 DFID (2005), *AIDS Communication*, London: UK Department for International Development

Tackling social complexity

Although CFSC programming is still relatively new and faces great challenges, it has additional support from the growing science of 'complex systems'. People act in a range of social settings and contexts with many different influences over long timeframes, and the difficulties of addressing this complexity of social life through linear, short-term development planning are increasingly recognised. Some have even argued that traditional 'command and control' methods of development planning are obsolete. Instead, development should focus on ensuring local actors' freedom and capacity for action – the rest will emerge, and should not be expected to follow prescribed patterns based on models of western economic development.[19]

Parallel conclusions emerge from much recent work on organisational learning in development, which promotes reflection on practice and experiential learning for all development actors – not just programme designers – and holds the potential to deepen participatory approaches to development.[20] Much of the new thinking in systems theory points to driving social innovation by decentralising initiative and control.[21] Certainly not an argument for laissez-faire globalisation, such approaches imply the need for a basic infrastructure for health, wellbeing and problem-solving capacities, as the foundation on which people can act for themselves.[22]

If recognition of the importance of the dynamics of social change has underpinned the approaches described above, it has also driven a growing interest in social movements in recent years. Independent initiative among civil society has been a key component of successful responses to HIV and AIDS – building on existing social networks, solidarity and motivation. The energy and sense of belonging that drove the early gay response in the US, or the social mobilisations around treatment action in South Africa, show a vitality and momentum that is often lacking in the externally designed initiatives of health and development agencies. The Panos Institute is currently engaged in research to explore the internal and external communication dynamics of social movements to understand where they can promote inclusive social change.[23]

There may be an inherent contradiction in trying to harness the energy of social movements to the more instrumental demands of development. But the spectre of identity- or emotionally based appeals being used to promote prejudice and fear – such as in some 'ethnic' and 'communal' conflicts in south Asia[24] – shows that the dynamics of social mobilisation are in urgent need of greater critical analysis. More specifically, there is a need to:

- strengthen participatory communication for social change thinking and practice
- adopt and widely support participatory approaches to communication for social change, enabling communities to tackle the barriers and challenges specific to their experiences and the character of local epidemics
- develop and support effective mechanisms for sharing evidence and learning of what has worked in particular settings
- develop the communication and problem-solving skills of the most affected communities
- develop the listening and facilitation skills of development practitioners.

19 See Rihani, S (2002), *Complex systems theory and development practice: understanding non-linear realities*, London: Zed Books

20 Vincent, R and Byrne, A (2006), 'Enhancing Learning in Development Partnerships', *Development in Practice* Vol 16 No 5

21 Castells, M (2000), *Network Society*, Oxford: Blackwell, pp61–9

22 As such they build on the 'positive' conception of freedom that enables people to act, rather than the 'negative' conception of freedom from constraint, that is linked to the untrammelled pursuit of economic gain – see Sen, A (2004), *Development as freedom*, Oxford: Oxford University Press

23 See *We are one but we are many*: www.panos.org.uk

24 Tambiah, S (1997), *Levelling Crowds: Ethnonationalist Conflicts and Collective Violence in South Asia*, New Delhi: Vistaar Publications

Focus on the media

Analysis of previous successes in the response to HIV and AIDS has pointed to the role of vibrant plural media in promoting debate and dialogue and breaking the silence over the epidemic.[25] Where HIV and AIDS have risen up the agenda of key influential media in a country, they have influenced public debate and, sometimes, the policy agenda.[26] The media can play a number of key roles in the fight against HIV and AIDS, including: providing information; stimulating and leading open and frank discussion; enabling PLWHA to air their views; challenging stigma with information and positive images; and encouraging leaders to take action.[27]

The success of entertainment-education in mixing popular soap opera formats with subject matter based on the realities, needs and passions of audiences facing HIV and AIDS are evident in South Africa, India, Tanzania, and other countries. Evaluations have shown that stimulating reflection and discussion on certain topics is at the heart of its efficacy.[28] An emerging 'third generation' of entertainment-education, such as the popular prime-time Nicaraguan television soap opera, *Sexto Sentido* (The Sixth Sense), aims to more consciously address the root causes of the everyday social problems and power inequalities faced by its young protagonists, stimulating debate and ultimately collective action and structural change.[29] Talk-radio and interactive TV discussion and chat shows such as the South African Community Health Media Trust's *Beat It*, have also proved powerful at engaging audiences by providing forums for sharing experiences and reflecting on the realities facing PLWHA.[30]

Participatory development has in the past driven an interest in 'small media' and the role of video, community radio, and more interactive media formats that reflect the emphasis on participation, ownership and self-determination.[31] There is a growing interest in the potential of new information and communication technologies for HIV and AIDS information and promoting debate.[32] Interest is also increasing in working with the media as a sector – for example, the Global AIDS Media Initiative, through which more than 20 media corporations from 13 countries produce and share public service content on HIV and AIDS.[33] The UK's Department for International Development (DFID) continues to support a range of media development initiatives in Africa and Asia, including a media development facility emerging from the Africa Commission, and has made further commitments to funding and support in its recent white paper on governance and poverty.[34]

More needs to be done to understand the media's 'public interest' role in promoting dialogue and diversity of voices, and how to support this in the current flux of changing global ownership, regulatory and funding patterns, and emergent electronic media. Given the fact that real-world indicators rarely determine the priority a social problem is given in the media agenda,[35] it is important to recognise that the media as a sector can revolve around commercialised content driven by the needs of advertisers and has an institutional tendency to reflect the interests of powerful global elites.[36] There is a need to better understand media environments – a concern reflected in recent work by Panos on media environments in Southern Africa[37] and the BBC World Service Trust's current research as part of the African Media Development Initiative.[38] Support for journalism is another key component of strengthening public interest media on HIV and AIDS – something that the Panos Global AIDS Programme, among others, has been pursuing through journalist fellowships and capacity development.[39]

25
Panos (2003), see footnote 2

26
Dearing, J and Rogers, E (1996), *Agenda Setting*, California: SAGE

27
UNAIDS (2005), *Getting the message across: the mass media and the response to AIDS* Geneva: UNAIDS

28
Singhall, A and Rogers, E (2003), see foootnote 2, p297

29
Tufte, T (2005), 'Entertainment-education in development communication: between marketing behaviours and empowering people', in Hemer, O and Tufte, T (eds) (2005), *Media and Global Change: Re-thinking Communication for Development*, Buenos Aires: CLASCO

30
See footnote 27

31
Bessette, G and Rajasumderam, C V (eds) (1996), *Participatory development communication: a West African agenda*, International Development Research Centre (IDRC)

32
See Exchange (2001), *Improving health, fighting poverty: the role of information and communication technology*, London: Exchange www.healthcomms.org/pdf/findings1.pdf; SAfAIDS (2005), *ICTs in the fight against HIV and AIDS*, Harare: Southern African HIV/AIDS Information Dissemination Service.

33
See www.thegmai.org

34
DFID (2006), *Eliminating world poverty: making governance work for the poor*, London: UK Department for International Development

35
See footnote 26

36
Herman, S and Chomsky N (1994), *Manufacturing consent: the political economy of the mass media*, London: Vintage; and Castells, M (1997) *The Power of Identity*, Oxford: Blackwells, pp313–28

37
Panos (2005), *Reporting AIDS: an analysis of media environments in Southern Africa*: www.panos.org.uk

38
African Media Development Initiative: www.bbc.co.uk/worldservice/trust

39
See www.panosaids.org and www.healthjournalism.net

Addressing the barriers to universal access 3

This woman was accused of giving her husband HIV and beaten by him for months before he left her for another woman. She now looks after her four children on her own. In desperation, she took the exceptional step of speaking to the media about her status, despite the strong social stigma attached to being HIV positive.
DIETER TELEMANS | PANOS PICTURES

Tackling barriers to universal access – such as stigma and discrimination, gender inequity and poverty – implies much more than technical development interventions. It requires communication for social change on many levels, to reduce the social, economic and legal inequalities that underpin social exclusion. This is one of the reasons HIV and AIDS have remained so difficult to address: good intentions and international development commitments have been hampered by questions of differential access to wealth and power that are protected by dominant global interests.

Combating stigma and discrimination

'With AIDS, the stigma faced by sex workers has increased tenfold.'
Meena Seshu
Sampada Grameen Mahila Sanstha (SAGRAM)[40]

Stigma and discrimination are still an everyday experience for PLWHA and vulnerable populations,[41] yet their complexity and diversity in practice, coupled with the failure to develop a greater understanding of their social roots, means they are often not addressed effectively. Stigma and discrimination are an example of where communication can be both part of the cause and the cure of social barriers. Stigma reflects existing social inequalities, since HIV is often associated with groups that are already marginalised in a way that compounds their marginalisation.

Communicating that HIV and AIDS need not be a death sentence, and that households do not have to face them alone can be a vital source of hope. It can also make inroads into the stigma surrounding the epidemic. Stigma is often anchored in the stress that HIV and AIDS place upon traditions of mutual support and reciprocity that characterise many extended families and households. Reactions of denial and avoidance can often be a desperate coping mechanism for those faced with the prospect of caring for family or friends when their own households are near collapse. In this context, providing resources to strengthen community responses – including the possibility of treatment – can give people hope.

40
POLICY (2003), *Moments in Time: HIV/AIDS Advocacy Stories*, p54, Washington DC: Futures Group International

41
Perkins, N and Mulyanga, S (2005), *My Right to Belong: stories of stigma re-education efforts across Africa*, Nairobi: ActionAid International Africa

Although few campaigns against stigma have been successful, breaking the silence around HIV and AIDS and moving discussions from the personal sphere to interpersonal and public arenas can help overcome it. Mass media have stimulated discussion through high-profile human interest stories featuring prominent individuals who put a human face to the epidemic.[42] A range of communication approaches have helped reduce stigma by promoting discussion and awareness of the realities of living with HIV and AIDS. Initiatives include: discussion forums and publications to raise awareness on the situation of older people as carers in Zimbabwe; youth care-givers who have promoted awareness about transmission risks, family reconciliation and community discussions in Zambia; radio listening clubs to promote discussions of stigma in Malawi; and awareness raising and training with healthcare worker and faith groups in Ethiopia and Rwanda.[43] Another way to tackle stigma is through sustained dialogue within communities, using participatory approaches such as Stepping Stones[44] and REFLECT, which allow community members to work with their own understandings and assumptions.

Communication can help challenge stigma and discrimination at a range of levels, including:[45]

- **advocacy**, to ensure that policy and laws do not perpetuate discrimination
- enacting **policies** in institutional contexts like schools, workplaces and healthcare settings
- promoting **accurate information and frank dialogue** with communities and households
- **human interest stories** in the media.

More research and ethnographic work is needed to understand and examine the local dynamics of discrimination and the solidarity that may challenge it in different settings.[46] There is also much to learn from social movements of PLWHA, who often develop 'resistance identities' to challenge their marginalisation and to redefine their position in society.[47]

Addressing gender inequity

In parts of Africa and the Caribbean, young women aged 16–24 are up to six times more likely to contract HIV than their male counterparts, while in sub-Saharan Africa 59 per cent of PLWHA are women.[48] Their limited access to resources and institutional power also places women at greater risk. In the face of this increasing 'feminisation' of the HIV epidemic, gender inequity must be urgently addressed.

Rooted as they are in the intimacies of everyday life and wider social norms and arrangements, gender relations are particularly difficult to address through specific 'interventions'. Where gender norms are reinforced from an early age and woven into the everyday 'way things are done', isolated messages about changing gender behaviours are swimming against an enormous tide. '… Any young man in Jamaica is constantly being told that he must have more than one woman, take risks and be adventurous to be a man, this is the essence of who he is as a man. This is far more powerful than a message about wearing a condom… There is no point talking to a young man about safe sex, when to be a man is to do the very things that lead him into unsafe behaviour…'[49]

42 Singhall, A and Rogers, E (2003), see footnote 2

43 See footnote 2

44 See www.steppingstonesfeedback.org

45 Parker *et al* (2002), *HIV/AIDS-related stigma and discrimination: a conceptual framework and an agenda for action*, Horizons programme, New York: Population Council

46 UNESCO (2003), 'HIV/AIDS Stigma and Discrimination: An anthropological approach', proceedings of the roundtable held on 29 November 2002, Paris: UNESCO

47 Stoller, N (1998), *Lessons from the Damned: queers, whores, and junkies respond to AIDS*, New York: Routledge

48 UNIFEM (2006), *Transforming the national AIDS response: mainstreaming gender equality and women's human rights into the three ones*, New York: United Nations Development Fund for Women

49 Interview by author with Hilary Nicholson of Women's Media Watch, Kingston, Jamaica, in April 2006

Gender inequality can only be addressed through a combination of locally owned communication processes and broader advocacy and social mobilisation to tackle some of its structural foundations. Concerted action is needed at a range of levels, including: legal and structural constraints in institutional contexts; community norms and practices; and interpersonal communication. It is also important to support women's efforts to gain greater control of their environment – not least the efforts of marginalised women such as sex workers, and networks of HIV-positive women.

It also needs to be recognised that communities are not homogeneous, but divided by power and gender inequalities. It is here that gender-sensitive communication approaches like Stepping Stones have proved useful for getting men and women talking about the usually taboo subjects of sexuality and gender, and to address some of the barriers to social change at the local level.[50]

However, there are limits to what can be achieved in any particular setting when the constraints of gender and poverty are rooted in wider social structures that stretch beyond the locality. Catherine Campbell's work on peer education among sex workers and mine workers in South Africa describes how complex gendered notions of risk, intimacy and trust are wrapped up with unprotected sex and skin contact, which may undermine HIV prevention and safer sex.[51] But these notions are also rooted in much broader patterns of poverty and migrant labour that are beyond local control. Current attempts to combine Stepping Stones' focus on interpersonal negotiations of gender and identity with the broader advocacy and social change that has often been part of the REFLECT popular education method, are promising in this regard.[52]

When addressing gender relations in HIV prevention, it is important to remember that HIV and AIDS are primarily social problems demanding social solutions. While it is important to prioritise prevention technologies that put more power into the hands of women – such as the long-neglected microbicides which have recently attracted welcome new funding – technical fixes can only be a part of a successful response. Even in South Africa, where recent campaigns to secure access to treatment have been an inspiration, the 'parallel epidemic' of gender violence remains a major problem.

Communication to tackle gender inequity includes:

- advocacy and social mobilisation to remove legal barriers and address social challenges such as gender violence, poverty and migrant labour
- equitable policies in different institutional contexts, such as schools and workplaces
- supporting existing networks and women's efforts to organise for gender equity
- gender-sensitive participatory communication approaches to tackle harmful gender norms and practices
- developing gender indicators to track progress on the above in country plans for universal access, and ensure plans are consistent with existing international gender conventions.[53]

50 Hadjipateras, A (2006), *Joining hands: integrating gender and HIV/AIDS*, London: ACCORD, HASAP

51 Campbell, C (2003), *Letting them die: why HIV/AIDS prevention programmes fail*, Oxford: James Currey. This link with masculine identity and risk is something studies of masculinity and HIV and AIDS have often shown, pointing to the need to work creatively within cultural traditions, to build on existing alternative notions of masculinity that stress support and responsibility; see Panos (1999), *AIDS and Men: taking risks or taking responsibility?* London: Panos

52 Combining REFLECT and Stepping Stones see http://217.206.205.24/Initiatives/reflectss.htm

53 See footnote 48

Strengthening health systems and integrating services

Sustained advocacy and social mobilisation are vital to secure the levels of government expenditure on health services and improvements on the wider health determinants that are needed for universal access to treatment. Adequate health services and access to affordable treatment will ultimately make the difference to poor communities' chances of surviving HIV and AIDS.[54] There must also be progress on the wider determinants of health to reach millennium development goal six for HIV and AIDS, and halt or reverse their spread by 2015.

The increasing trend towards integrating health services locally also provides communication opportunities. The World Health Organization (WHO) has already pioneered decentralised, integrated delivery of HIV and AIDS services in some places, as part of its integrated management of adult and childhood illness.[55] Such integration provides opportunities for communication and information on prevention, care and broader access and rights to health where people are accessing treatment. Decentralised, integrated services provide an opportunity to enhance the engagement and involvement of carers, while stigma and discrimination may become less of a barrier where voluntary counselling and testing (VCT) are accessed through routine links to other services – without making HIV testing a 'special case'.

Opportunities for more effective integration of TB and HIV communication are highlighted in the Panos 2005 publication, *Time for action on TB communication*, and reflected in Stop TB Partnership's global plan for 2006–15. Despite talk of the 'exceptionalism' of AIDS, this integration of services, information provision and engagement with communities should be seriously examined for other areas – sexual and reproductive health, mother-and-child health, nutrition and food security – where appropriate.[56]

HIV and AIDS communications should also emphasise links to broader social and economic development and stability. This would help galvanise the support and resources needed to fund the response. Epidemiologists describe HIV and AIDS as a 'long-wave event' – with a time lag between HIV infection and the onset of AIDS-related illnesses, and a further lag before the social, economic and political impacts on a country.[57] HIV and AIDS therefore need to be presented as a long-term challenge, demanding consistent attention and resources to address the social and economic impact on whole societies over many years.

54
Barnett, T and Whiteside, A (2002), *AIDS in the twenty-first century: disease and globalisation*, Basingstoke: Palgrave Macmillan, p342

55
Gilks, C F *et al* (2006), 'WHO public health approach to antiretroviral treatment against HIV in resource-limited settings', *The Lancet* Vol 368 5 August

56
Interact Worldwide (2006), *Intimate links: a call to action on HIV/AIDS and sexual and reproductive health and rights*, London: Interact Worldwide; ODI (2006), 'Food, nutrition and HIV: what next?' *Briefing Paper 7*, London: Overseas Development Institute

57
See footnote 54, p16

Focus on traditional health practitioners – effective local communicators

While the need for more health practitioners – and improved training for them – is a major concern in many developing countries, traditional medicine is a major resource that continues to be overlooked.[58] Traditional health practitioners are estimated to be the first point of call for as many as 80 per cent of people in Africa,[59] where there can be as many as 100 to each doctor, and up to 75 per cent in India.[60] Traditional healers provide accessible, affordable, culturally appropriate healthcare. They are valued and respected as counsellors and advisers – particularly in matters of relationships, sex and sexually transmitted diseases – giving them a potentially important role in HIV prevention.[61] Traditional and Modern Health Practitioners Together against AIDS (THETA) – a collaboration of traditional Ugandan healers and biomedical practitioners – is one of the best-documented examples of indigenous practitioners effectively promoting condoms, encouraging counselling and testing, and showing high levels of referral to the formal health system.

Unfortunately, a lack of consistency in support for collaborative projects, and scant evaluation data, has reinforced the reluctance to take traditional medicine seriously. The gulf between biomedical and indigenous approaches is often exaggerated, since notions of health and disease often have empirical and rational underpinnings – what Edward Green describes as a relatively widespread 'indigenous contagion theory'.[62] Given the urgent need to upscale HIV prevention efforts, much more needs to be done to build collaboration and strengthen links and mutual referral between the different health systems. This should not be a substitute for strengthening a country's health system, but used instead to increase the coverage of healthcare and support services, effectively building on communities' existing human resources for health. In fact, the customary wide remit of traditional health practitioners may help strengthen intersectoral links to other health issues and interventions, which are increasingly important in addressing HIV and AIDS.

58
Traditional medicine covers a broad range of practices including herbalism and spiritualism, see Green, E (1999), *Indigenous theories of contagious disease*, London: SAGE

59
UNAIDS (2000), *Collaboration with traditional healers in HIV/AIDS prevention and care in sub-Saharan Africa: a literature review*, Geneva: UNAIDS

60
Mane, P and Maitra, S (1992), *AIDS prevention: the socio-cultural context in India*, Bombay: Tata Institute of Social Sciences

61
See footnote 59

62
See footnote 58

Effective communication for scaling up universal access

4

Sympathetic but critical engagement of existing cultural practices can deepen participatory communication approaches; traditional healers are often respected counsellors and advisers on health and relationships.
ERIC MILLER | PANOS PICTURES

Communication, dialogue and negotiation are central to coordinating the wide range of stakeholders working towards universal access, and developing the accountability, transparency, and meaningful involvement of PLWHA that are essential to a relevant and effective response.

Building on what is there

'We look at what people are already doing, we share those experiences and learn from each other… We ask people, "what skills do you already have, and are already using to effect change in your communities?".'

Ludfine Opudo
Society for Women in AIDS in Kenya[63]

A key element in the next steps to universal access emerging from the country consultations in 2005/6 was to 'build on what is there at all levels'. This deceptively simple phrase encompasses the need to: harmonise existing funding and programming efforts; strengthen existing initiatives; and recognise local priorities and the experiences of PLWHA. It is important to recognise, however, that the latter is made difficult by the dependence on external development actors for resources and inputs. Recent critiques have shown that 'participatory' approaches often co-opt people into powerful, pre-set development agendas, under the guise of 'authentic' local participation.[64] This has led some to explore who sets the terms of different 'spaces of participation', and to assess how much real control is in the hands of different groups. Are marginalised people invited to the table of the powerful who set the terms of the encounter, or are there different spaces where marginalised people feel more at home?[65] Although we cannot explore the details here, this new thinking in governance and participation may have important critical insights for participatory communication approaches, ensuring that the most affected people genuinely drive the response and that participation does not amount to niche marketing of solutions conceived by external experts.

63
See footnote 40

64
Mosse, D (2001), 'People's Knowledge, Participation and Patronage: Operations and Representation in Rural Development', in Cooke, B and Kothari, U (2001), *Participation: the new tyranny?* London: Zed Books

65
Cornwall, A (2004), 'Spaces for transformation? Reflections on issues of power and difference in pariticipation in development' in Hickey, S and Mohan, G (eds) (2004), *Participation: from tyranny to transformation: exploring new approaches to participation in development*, London: Zed Books

Another danger is that responsibilities are off-loaded onto poor communities under the guise of them being considered 'resourceful' or 'resilient', with community engagement seen as a way to reduce the burden on health and social systems.[66] Many community-based organisations in Africa have risen to the challenge of delivering HIV treatment on a significant scale while they await the much-needed public sector response. Some even provide a comprehensive, free-of-charge, 'total patient care' package of services: testing, treatment, monitoring of treatment, and support for adherence.[67] Many such community responses evolved because inadequate transport links and tight prescribing regulations were hampering access to treatment in clinical settings. The same study found that community programmes could often achieve an instant expansion of services with adequate funding for antiretroviral (ARV) drugs.

The experience of such organisations points to the need for advocacy around: support for community-based responses; funding for purchasing ARVs; operational costs and support; and polices to support service decentralisation. However, this must be in the context of fully resourcing health systems: while the initiative of such communities is an inspiration, it must not be an excuse to avoid government responsibility.

Focus on HIV and culture

Cultural beliefs and practices are a central part of life in any setting. They affect people's capacity to accept or stigmatise PLWHA, their willingness to engage with emerging treatments, and the patterns of care that are embedded in family and community relationships. Cultural assumptions also shape the institutional and policy processes of international development, which can hinder local initiatives and prevent the expression of local needs.[68]

Many of the positive examples of engaging culture involve the creative re-working of traditions, which may otherwise perpetuate risky practices for HIV transmission. These include finding symbolic alternatives to 'cleansing' rituals that previously involved sex in East and Southern Africa, or reviving practices like non-penetrative 'thigh sex' among the Nguni of Southern Africa.[69] Such approaches rely on the fact that culture is dynamic: traditions are not fixed barriers to social change and development. An understanding of culture is therefore key to unravelling the challenges of stigma and discrimination, which often use cultural and social differences to mark out social groups for blame and negative treatment.

Despite a growing interest in the role of culture – reflected in the early work of UNESCO and UNAIDS[70] and the prominence accorded to culture in the Africa Commission's recent report – development interventions show little systematic understanding or approach to culture.[71] Sympathetic but critical engagement of culture can deepen participatory communication approaches, by moving beyond the 'tailoring' of externally defined communication and messages to value and support the novel forms of expression developed by people in their own contexts and struggles.

Ultimately, more ethnographic research is urgently needed to understand cultural processes, including cultural needs assessments and local cultural analysis. Appropriate ways to evaluate cultural processes must also be developed.

66 UNESCO (2005), *HIV and AIDS Treatment Education: a critical component of efforts to ensure universal access to prevention, treatment and care*, Paris: UNESCO

67 UNAIDS (2005), *Expanding access to HIV treatment through community based organisations: UNAIDS best practice collection*, Geneva: UNAIDS

68 Vincent, R (2005), *What do we do with culture? Engaging culture in development*, Exchange: London

69 Blair, C *et al* 1997, in Singhall, A and Rogers, E (2003), see footnote 2, p220

70 Vincent, R (2005), reviews recent initiatives, see footnote 68

71 Gould, H and Marsh, M (2004), *Culture: Hidden Development*, London: Creative Exchange

Supporting country-driven processes and the wide involvement of stakeholders

'People should realise the importance of grassroots level as it is a great problem to our leaders, because the people who make laws and policies end up doing the totally different thing from what they are promising.'

TAC member
South Africa

There are two main communication challenges in any country: coordinating and promoting dialogue among the different stakeholders and initiatives in the response to HIV and AIDS and developing feedback mechanisms that will improve the effectiveness of the response. In recognition of successful home-grown and country-driven responses, there have been recent attempts to find mechanisms for such coordination and dialogue. In 2004, UNAIDS developed the Three Ones initiative, which encouraged the use of one national framework for action, one national AIDS coordinating authority and one agreed country-level monitoring and evaluation system in each country. At the same time, the Global Fund for AIDS, TB and Malaria – the major source of multilateral HIV and AIDS funding – has sought to coordinate partners, including civil society and PLWHA, through its country coordination mechanisms. Civil society involvement in these structures, however, has proved uneven. A study by the International Council of AIDS Service Organizations (ICASO) found that NGOs and vulnerable populations were inadequately represented, and lacked the capacity for involvement and effective representation.[72] At the same time, while increasing harmonisation and avoiding duplication in funding and programming is important, these frameworks must not be so rigid that they restrict the diversity and vitality of local responses.

Similarly, monitoring and evaluation has the potential to provide all-important feedback that can improve future action. Far too often however, monitoring and evaluation is overly technical and driven by external priorities and indicators. This reduces its potential to support learning and improve the relevance and effectiveness of activities on the ground.[73]

Multilateral funding mechanisms, such as the Global Fund and World Bank Multilateral AIDS Programme, have more potential to be led by national government in partnership with civil society and affected communities than bilateral arrangements.[74] Strengthening commitment to such mechanisms should therefore support country-driven HIV responses. But recent studies also show that for such mechanisms to be effective, their efforts must be harmonised and aligned.[75] Nevertheless, finance flow to the Global Fund has been inconsistent since it inception, and further shortfalls of US$500 million for grants are predicted in the sixth round, despite the recent donation of US$500 million over five years from the Gates Foundation.[76]

72 ICASO (2004), *NGO perspectives on the Global Fund,* Toronto: International Council of AIDS Service Organizations

73 International HIV/AIDS Alliance and ICASO (2004), *Discussion paper: civil society and the 'Three ones'*, Brighton: International HIV/AIDS Alliance

74 International HIV/AIDS Alliance (2004), 'What's preventing HIV prevention?', policy statement to UNAIDS, Brighton: International HIV/AIDS Alliance

75 ODI (2006), 'Scaling-up the HIV/AIDS response: from alignment and harmonisation to mutual accountability', *Briefing Paper 9*, London: Overseas Development Institute

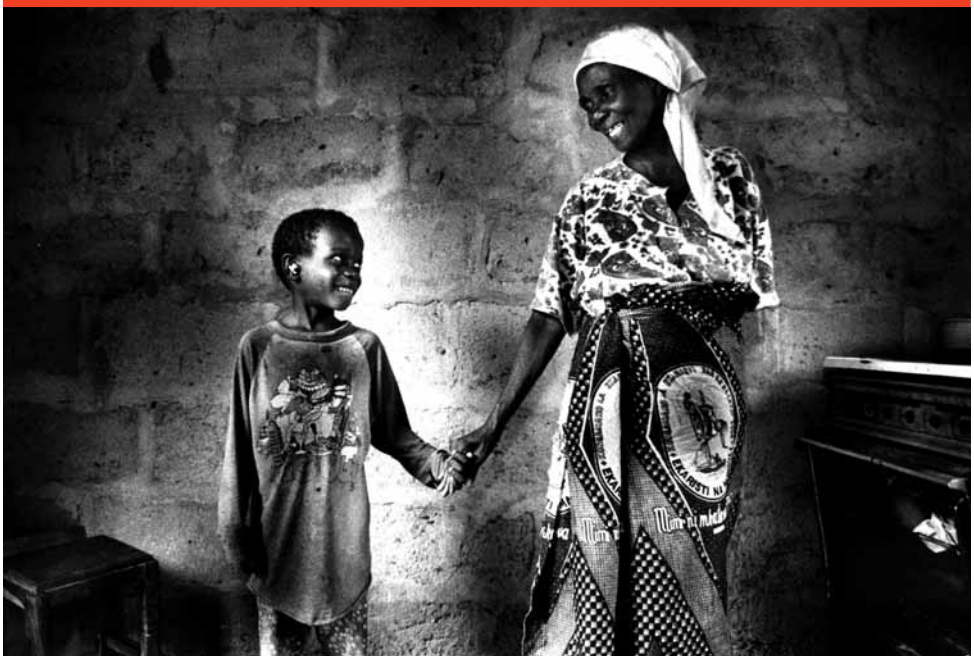
76 Feacham, R, Global Fund director quoted by Reuters, 9 August 2006

Where mobilising all stakeholders is important, the more meaningful involvement of PLWHA (MIPA) remains a priority. The greater involvement of PLWHA (GIPA) in policy formulation and service delivery at all levels was first backed at the 1994 Paris AIDS summit. GIPA aimed to enhance equity and make the response more relevant and effective. In practice however – and in contrast to some independent civil society initiatives and social movements – PLWHA involvement in the institutionalised response remains tokenistic, with recent research showing that PLWHA are only occasionally involved in making policy or managing initiatives.[77] To make meaningful involvement of PLWHA a reality there is a need for adequately resourced training for PLWHA, and the development of organisational capacity to create a supportive institutional environment for their involvement. NGO studies have similarly highlighted the need to resource effective capacity-building tools to enable the effective participation of civil society and PLWHA in the Three Ones at country level.[78] There must also be genuine political commitment to tackling the fundamental drivers of the epidemic: the barriers to PLWHA involvement are often the poverty and structural constraints that increased their vulnerability to HIV in the first place.

77
Cornu, C and Attawell, K (2003), *The involvement of people living with HIV/AIDS in community-based prevention care and support programs in developing countries: a multi country diagnostic study*, New York: Population Council and Brighton: International HIV/AIDS Alliance

78
See footnote 73

Communication for integrated prevention, treatment and care 5



Families where grandparents look after their grandchildren have become the norm. Supporting these relationships and relieving the care burden where this is needed are important and necessary services.
DIETER TELEMANS | PANOS PICTURES

The potential of treatment means that HIV and AIDS are no longer seen to deal a definite death sentence. This has removed some of the stigma, bringing renewed hope and the chance to reinvigorate prevention efforts. Nevertheless, prevention, treatment and care must be equally prioritised, and communication interventions should mutually reinforce all three if universal access to treatment is to be sustained in the longer term. Access to treatment can be an incentive to get tested, and provide opportunities for enhanced prevention. At the same time, prevention is key to reducing new infections, without which universal access to treatment will be difficult to sustain. Adequate support to care is also vital to address the long-term impacts of HIV and AIDS on households and societies and to counter the despair and isolation that can undermine the response.

Accelerating prevention

A first communication challenge for prevention is to maintain the commitment and investment in proven interventions at a scale that can have an impact on the pandemic. Recent figures suggest that coverage of essential HIV prevention services currently reach less than one in five of people at risk globally.[79] Only 9 per cent of HIV-positive pregnant women are receiving ARV prophylaxis and fewer than 50 per cent of young people – who account for half of all new infections – are properly educated about HIV and AIDS.[80] In the light of these figures, UNAIDS, WHO and others have called for governments to 'intensify' HIV prevention.

79
UNAIDS (2005), *Intensifying HIV prevention*: UNAIDS position paper, Geneva: UNAIDS

80
UNAIDS (2006), *Declaration of Commitment on HIV/AIDS: five years later*, Report of the Secretary General, Geneva: UNAIDS

Communication and engagement with the most affected groups is another priority, following the basic communication principle of tailoring prevention efforts to the character of the epidemic in different settings. Recent evidence points to a failure in many countries to resource and address prevention among high-risk populations.[81] For example, less than 20 per cent of injecting drug users worldwide receives prevention services.[82] In some countries of Eastern Europe and Central Asia – where drug use is a significant driver of the rapidly expanding epidemic – this failure to employ evidence-based prevention is compounded by unhelpful laws and policies that prohibit drug substitution therapy and criminalise drug users. The same combination of inadequate prevention services and counterproductive laws characterise the response to sex workers and men who have sex with men in many countries – a dangerous backwards step at a time when bold, focused initiatives are needed to stem a preventable second wave of the HIV pandemic.

There is a need for clear HIV prevention communication based on evidence, rather than ideology. The essential components of prevention grounded in public health principles and evidence are commonly known,[83] although the balance of prevention practices has always been a matter for debate. Concern has grown in recent years however, over the vigorous promotion of 'abstinence only' messages and interventions. One-third of all prevention funds available through the US President's Emergency Plan for HIV/AIDS Relief (PEPFAR) are earmarked for this – an emphasis that apparently rests on Uganda's early response to the epidemic. Yet a review of the evidence suggests that a balanced combination of prevention interventions was effective in Uganda, where the broad mobilisation of society was accompanied by open dialogue and communication. Delayed sexual debut and partner reduction – not abstinence – were predominantly behind the success in Uganda and elsewhere. Another important factor was the empowerment of women – a deliberate government policy that saw high numbers of women entering employment in Uganda.[84] US research shows that when those who have taken a pledge of no sex before marriage do have sex – and many of them do – the shame and embarrassment makes them less prepared to deal with it and protect themselves.[85] At the same time, open discussion of all options in sex education – rather than the moral absolutes of abstinence campaigns – has been linked with delayed sexual debut.[86]

Moralistic US policies that liken prevention work with sex workers to the promotion of sex trafficking have seriously hampered work with a key vulnerable population. This dangerous moralistic approach has also underpinned the rejection of needle exchange interventions – a public health measure of proven success, which plays an important role in preventing the 'bridging' of HIV into the general population.[87]

Communication to strengthen HIV prevention needs:

- a campaign for intensified prevention activities that are sustained and at scale
- to work with the most at-risk groups to design effective prevention services that are based on public health principles and relevant and engaging prevention communication
- advocacy for HIV prevention and communication interventions that are based on evidence, not ideology
- strong leadership to promote these, even where they are politically controversial.

81
Panos (2006), *Keeping the Promise? A study of progress made in implementing the UNGASS Declaration of Commitment on HIV/AIDS in seven countries*, London: Panos

82
See footnote 80

83
See footnote 79

84
Green, E (2003), see footnote 2

85
Bruckner, H and Bearman, P (2005), 'After the Promise: the STD consequences of adolescent virginity pledges,' *Journal of Adolescent Health*, April, pp271–8

86
CHANGE (2004), *Debunking the myths in the US Global AIDS strategy: an evidence based analysis*, Maryland: Centre for Health and Gender Equity

87
Gill, P (2006), *Body Count: how they turned AIDS into a catastrophe*, London: Profile Books

The hope and potential of treatment

'I had never been tested… it was only when we had listened to all that information on the drugs that I made my decision. I got myself tested on Wednesday. I finally realised that even with HIV there is always hope!'

Person living with HIV
Senegal[88]

Free HIV treatment must be made more widely accessible, and people must know about it, since numerous studies have shown that fees affect the uptake and adherence to treatment, with people making trade-offs with expenditure on food and shelter.[89] Increasing accessibility of treatment throws up a number of communication challenges: raising awareness of its availability, ensuring individuals and communities have the knowledge and information they need about the treatment and mobilising them to provide support and care.

Advocacy is also needed around access to basic health determinants such as adequate nutrition and water, and the relevant financial, technical, social and political support for health systems that will make universal access sustainable. A sobering reminder of these broader challenges is the observation that, even if effective HIV treatment was a glass of clean drinking water, 75 per cent of the world's population would not have access to it.[90]

Communication and advocacy have underpinned the impressive increases in the number of people receiving ARV treatment (ART) in recent years, with the tenacity of organisations like TAC in South Africa, and the Brazilian government's firm negotiations which brought substantial reductions in drug prices. Continued advocacy is needed for price reductions in the newer 'second-line' combinations, and related diagnostic and monitoring technologies. At the same time, governments need information and advocacy to make effective use of generic drugs under World Trade Organization (WTO) TRIPS (trade-related aspects of intellectual property rights) provisions, which are often circumvented under political pressure in bilateral government negotiations.[91]

Information and communication are just as important as drugs and medical care in preparing for treatment. Communication and education around ART have been shown to improve health outcomes and quality of life, contributing to greater uptake of VCT services, and improving adherence to treatment.[92] When ARVs are introduced into communities, people taking the drugs and those supporting them need to understand a range of issues. Information around treatment must therefore be free of medical terminology, accessible and in local languages, and developed with the participation of communities themselves, to ensure it is appropriate and relevant. It must meet the needs of everyone in the community, including minority groups, non-literate people and children.[93] A range of participatory treatment literacy materials that can be adapted for local use have been developed by TAC, and the International Treatment Preparedness Coalition (ITPC).[94]

88
International HIV/AIDS Alliance (2005), *Community Engagement for Antiretroviral Treatment: a training manual for community-based organisations, non-governmental organisations & people living with HIV in Africa* – pre-publication draft, Brighton: International HIV/AIDS Alliance, p12

89
Attawell, K and Mundy, J (2003), *Provision of anti-retroviral therapy in resource-limited settings: a review of experience up to August 2003*, London: HSRC/DFID

90
Singhal, A and Rogers, E (2003), see footnote 2, p371

91
Correa, C M (2006), 'Implications of bilateral free-trade agreements on access to medicines', *Bulletin of the World Health Organization*, May: 84 (5)

92
UNESCO/WHO (2006), cited in Dunn, A (2006), *Anti-retroviral drugs and treatment literacy*, London: Exchange

93
Dunn, A (2006), see footnote 92

94
Dunn, A (2006), p3, see footnote 92

Information and communication needs around treatment include:

- the promotion of VCT, a prerequisite for starting treatment
- clear criteria for when treatment should be started and equitable ways to decide who should be prioritised for treatment
- the positive benefits of treatment
- different treatments and drug regimens (including side effects)
- the importance of adherence
- strategies for adherence
- how communities can support those on treatment
- clinical and support services that are available
- treatment and test costs
- other related costs
- the importance of continued protective behaviours
- how to take ARVs
- how ARVs work
- looking after the drugs
- effects on daily life, including sex
- ARVs and pregnancy
- positive living, including nutrition.[95]

Involving PLWHA in counselling and community mobilisation around treatment has enhanced uptake and adherence to drugs in some settings,[96] while services developed under the leadership of PLWHA have been able to flexibly address the needs of those most affected – including underserved groups such as women and children.[97] PLWHA in South Africa and Mozambique have developed simple, effective communication tools such as 'treatment diaries' to help keep a record of treatment history, and adherence partners or buddies and support groups to encourage those on treatment.[98]

Where there is less existing mobilisation around treatment, communication interventions can foster a supportive community environment to help people cope with all aspects of treatment, including adherence. Engaging with local leaders[99] and working with the media to raise awareness of treatment issues and build community support for treatment are important in this regard.[100]

Mobilising for VCT

Testing is a prerequisite to starting treatment, yet less than 1 per cent of adults aged 15–49 currently access VCT. Although there is a need to increase accessible facilities, the communication challenge is social mobilisation to encourage people to be tested. Awareness that HIV treatment is free gives people an important incentive to get tested: Brazil's 'Be in the Know' awareness initiative in 2003 saw a 30 per cent increase in numbers testing in one year, while in Khayelitsha, South Africa, numbers increased from 1,000 in 1998 to more than 12,000 in 2002, following the introduction of ARVs.[101]

95
This list was drawn from the following: UNESCO (2005), *HIV and AIDS Treatment Education: a critical component of efforts to ensure universal access to prevention, treatment and care*, Paris: UNESCO; and International HIV/AIDS Alliance (2004), *Anti-retroviral treatment in Zambia – a study of the experiences of treatment users and health care workers*, Brighton: International HIV/AIDS Alliance

96
UNESCO (2005), see footnote 95

97
UNAIDS (2005), *Expanding access to HIV treatment through community based organisations: UNAIDS best practice collection*, Joint United Nations Programme on HIV/AIDS

98
UNESCO (2005), p16, see footnote 95

99
Ritzenthaler, R (2005), in Dunn, A (2006), see footnote 92

100
A recent Panos briefing paper for journalists on access to treatment supports journalists to strengthen awareness and debate around this issue: Panos (2006), *Antiretroviral drugs for all? Obstacles to access to HIV/AIDS treatment*, London: Panos

101
Dunn, A (2006), see footnote 92

Ongoing counselling and continued communication around maintaining prevention behaviours must be tailored to PLWHA, to prevent 'treatment optimism' or 'disinhibition'. In some settings, there may be a need to counter ideas that treatment amounts to a 'cure' – in Kenya, for example, this belief led to temporary reductions in preventive behaviours such as condom use.[102]

For communication around treatment to be effective, it is necessary to:

- directly involve affected communities and PLWHA in developing appropriate communication materials and approaches to promote treatment and VCT
- strengthen local communication capacity to empower people to find their own context-relevant solutions
- support mechanisms for sharing communication materials and approaches, and networking between different communities and initiatives
- advocate for a reduction in ARV prices and support governments to make use of generic drugs under WTO TRIPS provisions.

Addressing the neglect of care

While initiatives to scale up ART have had some success, many people still have no access to other essential services, such as care and support,[103] and little attention has been paid to the communication and engagement necessary to ensure effective care for PLWHA. The majority of PLWHA in developing countries are cared for in their households, predominantly by women, so there is an important gender component to this invisibility. Much of the effort and costs of home-based care are hidden, and fall on care-givers and communities who are least able to carry the burden.[104]

Communication challenges for effective home-based care include:

- recognising the important role of care and engaging with carers
- support for carers – including resources, training where appropriate, and mobilising social and psychological support
- effective coordination of the range of professional support services needed
- information and support for carers to ensure they take appropriate measures to protect themselves from tuberculosis (TB) and HIV infection.

It is important that communities get the necessary support and resources from the formal health system, which is the responsibility of the state. There is a need to find ways to build on existing care and support structures, without exploiting already stretched households or entrenching inequalities of gender and wealth.

It is also vital to engage and communicate with households and communities to find appropriate options for care of orphans and vulnerable children. There are a range of options, from public residential care to informal fostering and voluntary support in the community.[105] In many settings where extended households are the norm, traditions of fostering children are strong, and there is a reluctance to place children in institutions that are outside local networks of reciprocity and support. Communication with young children brings with it a set of distinctive communication challenges: it is important to find ways to listen to children and help them express their needs. In some cases, children need support to claim their rights to land inheritance – this is particularly so in the case of girls, who may be disadvantaged in this regard.[106]

102 Global HIV/AIDS Prevention Working Group (2004) *HIV/AIDS prevention in the era of expanded treatment access*, Gates Foundation: www.gatesfoundation.org

103 See footnote 81

104 Akintola, O (2004), *The gendered burden of home-base care giving*, Durban: Health Economics and HIV/AIDS Research Division (HEARD)

105 Dunn, A (2004), *HIV/AIDS: what about very young children?*, London: Exchange

106 Cabrera, C, Pitt, D and Staugard, F (1996), *Aids and the Grassroots: problems, challenges and opportunities*, Nairobi: Ipelegeng Publishers

Preparing for death and bereavement is another big communication challenge. Enabling people to die as dignified a death as possible helps to reduce the denial and stigma that accompany HIV and AIDS and supports people to live positively with HIV and AIDS. It also has the potential to reinforce prevention and treatment, by building the overall capacity of communities to face a future that entails coping with HIV and AIDS in a sustained and ongoing way. Effective palliative care is an important basis on which to maximise the quality of life for those with HIV and AIDS and provide the best possible death for those with advanced illness.[107] PLWHA have developed a range of communication innovations to help people die in dignity, and help relatives remember those they have lost and prepare for a future without them. In South Africa, memory boxes gather together the personal effects of loved ones, to ensure that they are remembered,[108] while memory books support communication between children and their parents on all aspects of HIV and AIDS, and help prepare children for the death of a parent – bringing together personal messages, photos and mementos, and plans and information about relatives and carers.[109]

107
ID21 (2006), 'Palliative Care: a human right', *id21 health insights:* 8

108
Singhall, A and Rogers, E (2003), see footnote 2

109
Healthlink Worldwide (2006), *Building children's resilience in a supportive environment: reflecting on opportunities for memory work in HIV responses*, London: Healthlink Worldwide

Conclusions and recommendations: strengthening existing responses 6

Building on existing strengths and initiatives is a challenge for communication initiatives around HIV prevention, treatment and care in communities affected by HIV and AIDS.
PEP BONET | PANOS PICTURES

Our review of the communication challenges for HIV prevention, treatment and care shows that a common concern is to build effectively on existing responses and initiatives in communities most affected by HIV and AIDS. Local initiative and response often takes place with or without the public health systems and development initiatives that aim to tackle HIV and AIDS. Nevertheless, these multiple and informal responses must be supported and strengthened. This will require renewed emphasis on participatory communication for social change, supplemented by further work to understand the dynamics of existing social and cultural responses, including social movements.

A willingness to explore participatory development approaches that genuinely work with the grain of local need and respect local initiative cannot be an excuse for neglecting the fundamental social challenges of HIV and AIDS. These demand an investment of energy and resources to strengthen public health systems and social support infrastructure in many developing countries. Political will is also needed to address the inequity and poverty that drive the epidemic, and to work for legal and institutional policy frameworks that will address the social and structural barriers to the response.

It will take sustained advocacy to keep up the pressure on governments to 'deliver the promise'. Communities most affected by HIV and AIDS will find creative responses to the many challenges of HIV prevention, treatment and care. But they need to access the lessons already learned by others in responding to the epidemic, and guidance from a growing array of communication approaches and tools, skills and expertise. It is the responsibility of development practitioners to bring these to their endeavour. As was concluded above, this implies a greater commitment to developing and funding participatory communication for social change approaches, as an integral part of realising universal access.

This review consolidates lessons learned about the successes and challenges of communication in HIV prevention, treatment, care and support. The following recommendations aim to maximise the contribution of communication in support of universal access by 2010:

Mainstreaming communication for effective coordination of the response

- Ensure that country plans for universal access have a communication strategy that clearly identifies priorities for communication around each of prevention, treatment and care, and the necessary resources and expertise to put it into practice
- Maximise accountability and transparency of the HIV/AIDS response through country-level plans developed with meaningful input of those most affected, and their involvement in monitoring national and international commitments, policies and funding processes
- Promote simple and manageable monitoring and evaluation that strengthens learning for more effective practice on the ground, and facilitate networking to share lessons learned
- Support networks of PLWHA and inclusive social movements to strengthen their communication capacity, and to mobilise around universal access to prevention, treatment, care and support
- Work with the most affected and at-risk groups to ensure communication around prevention, treatment and care interventions is focused on the character of local epidemics and does not neglect prevention and care.

Communication to tackle the drivers of HIV and AIDS and long-term social impact

- Promote a large-scale, purposeful dialogue on the underlying and core causes of HIV and AIDS – first with the most affected groups and subsequently with wider groups of stakeholders in the response
- Promote advocacy and social mobilisation to tackle social barriers to universal access such as poverty, gender inequity, stigma and discrimination, and inadequate health systems, through: supportive laws and government policies; supportive institutional policies; and community dialogue, debate and action
- Promote dialogue and debate at all levels on the long-term social impact of HIV and AIDS on social infrastructure, communities and households, to inform policies and initiatives that will mitigate such impact.

Strengthening communication thinking and practice

- More systematically strengthen the role of the media and new information and communication technologies in promoting awareness, dialogue and debate, and to amplify the voices and experiences of those most affected
- Raise awareness of the importance of interactive and participatory communication approaches that look beyond ‘messaging’ and social marketing
- Further develop and fund participatory communication for social change approaches to strengthen civil society and community communication capacity, and to enable innovative, relevant and locally owned responses
- Build on existing community communication capacities and responses, such as inclusive social movements and creative cultural practices.

Contact us

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