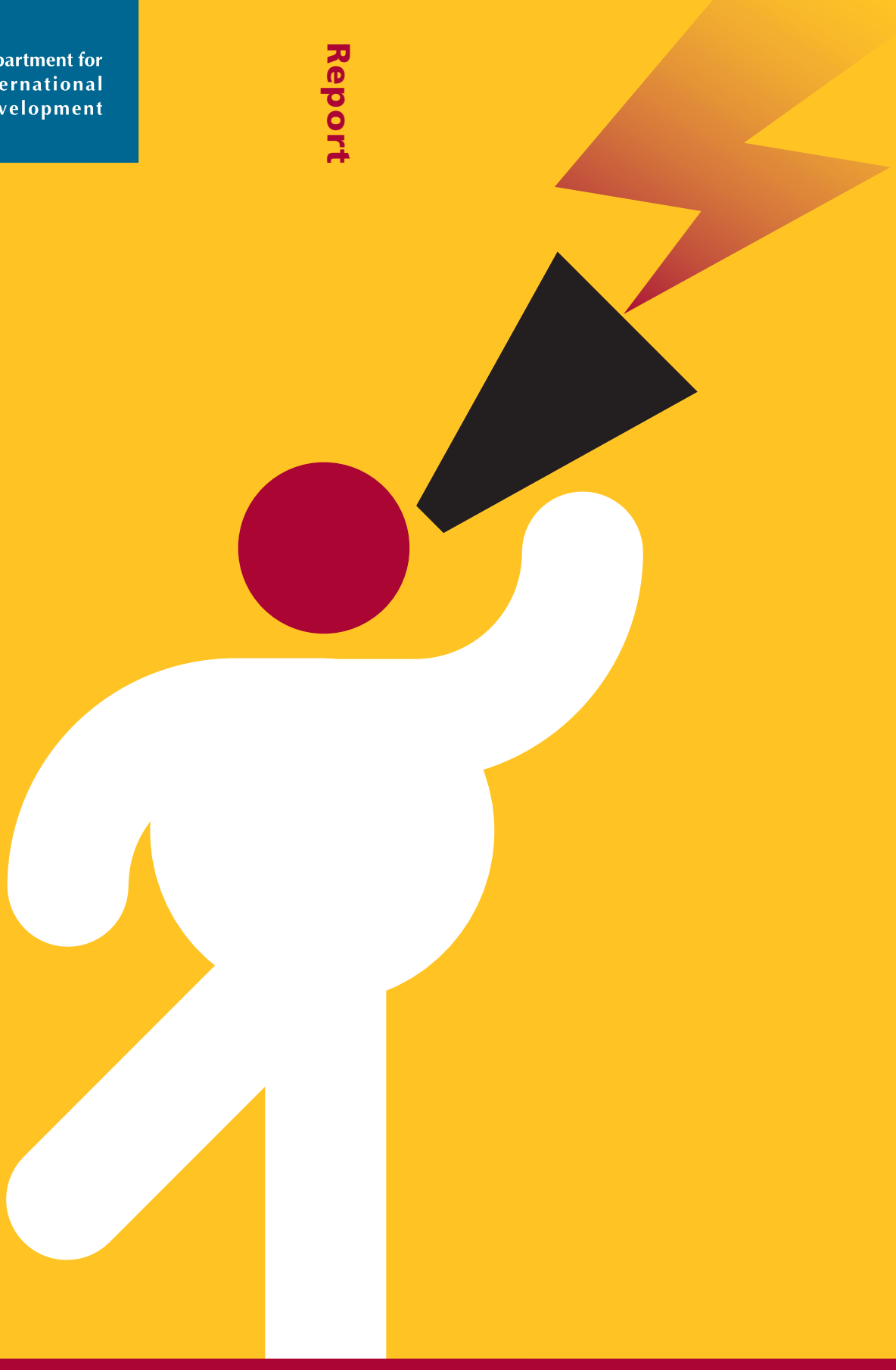
DFID Department for International Development

Report



Information and Communication for Development

AIDS Communication

September 2005

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Acknowledgements

This paper was written and edited by Dr Andrew Skuse of the School of Social Sciences, University of Adelaide and Fiona Power of DFID's Information and Communication for Development Team (ICD). It was peer-reviewed through a process managed by Healthlink Worldwide. The authors would like to thank the following people for their comments and contributions: Peter Gordon (consultant), Ewan Armstrong (consultant), Andrew Chetley (Exchange Programme), David Clarke (DFID), Phil Evans (DFID), Nicky Woods (DFID), Mary Myers (consultant), Thomas Scalway (PANOS), Hazel Slavin (consultant), Nick Ishmael Perkins (consultant), James Deane (Communication for Social Change Consortium), Tahir Turk (consultant), Bruce Mackay (Futures Europe), Sian Long (Save the Children UK), Warren Feek (The Communication Initiative), Aisha Yousef (Centre for International Child Health), Sue Goldstein (Soul City: The Institute for Health & Development Communication), Lori Hieber Giaradet (WHO), Sara Page (SAfAIDS) and Justine Sass (consultant).

Designed by Grundy & Northedge

Acronyms and abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral therapy
BCC	Behaviour change communication
BCI	Behaviour change interventions
CBOs	Community-based organisations
CFSC	Communications for social change
CSO	Civil society organisation
DFID	Department for International Development
FBOs	Faith-based organisations
FHI	Family Health International
GFATM	Global Fund for AIDS, TB and Malaria
HIV	Human Immunodeficiency Virus
ICT	Information and communication technologies
IEC	Information, education and communication
MAP	Multi-country AIDS Programme
MFMC	My Future is My Choice
MSF	Médecins Sans Frontières
NAC	National AIDS Coordinating Authority
OHCHR	Office of the UN High Commissioner for Human Rights
PEPFAR	President's Emergency Plan for AIDS Relief
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission
STI	Sexually transmitted infection
UNAIDS	Joint UN Programme on HIV and AIDS
UNESCO	UN Educational Scientific and Cultural Organisation
UNICEF	UN International Children's Fund
VCT	Voluntary counselling and testing
WHO	World Health Organisation

Contents

A rapid reference guide to the key themes presented in this paper can be found in **Appendix 1**. In **Appendix 2** you can find a guide to the sensitive use of language to describe HIV and AIDS. In **Appendix 3** a list of useful on-line resources related to AIDS communication is provided and in **Appendix 4** you can find a reference list.

1 Introduction

1.1 The purpose of this paper is to provide a resource for DFID staff on the role of communications in its project, programme and policy work on HIV and AIDS. In doing so it highlights the practical experience of donors, non-government agencies and community-based organisations and recognises that mass and participatory communications, as well as peer education and outreach activities, play a vital role in support of human and social development. More specifically, this recognition is evident in the breadth and scope of communications material published in support of HIV awareness and prevention, risk and stigma reduction, the social marketing of condoms, AIDS treatment and in AIDS care and support developed over the past 10 years across Africa, Asia, Latin America and the Caribbean (UNAIDS 2000a). In drawing on this material, this paper advocates for:

- A shift away from the often inappropriate and unrealistic targets for changing behaviour that are set at project or programme level, towards a stronger emphasis on rights to education and information, community participation and dialogue.
- An integration, where possible, of communications for HIV prevention, AIDS treatment and care.

1.2 DFID staff working at country level will be regularly approached with proposals for AIDS communication activities (which includes communication for prevention, treatment and care). It is important that these proposals fit within DFID's priorities, are technically sound and represent value for money. This paper provides DFID staff with a theoretical framework that aims to promote a broad-based multi-method approach to communications. In other words, an approach which does not rely on a single communication methodology or channel, which takes into account people's real lives and what influences them and which is linked to and supports the delivery of health services and essential commodities. This framework is underpinned with recommendations about how to put it into practice, including suggestions for how DFID – internally and at community, national and international levels – can support AIDS communication activities.

1.3 Existing methods of communication – from the mass-media branding of condoms, to soap operas targeting risk-taking behaviour, to numerous participatory and interpersonal interventions - contribute to the creation of information-rich 'environments' in which HIV prevention, AIDS treatment and care efforts are 'enabled' or strengthened and in which stigma can be reduced. Recognising the role of open public debate is equally important. The role that mass media and civil society play in shaping HIV and AIDS-related policy, addressing issues of stigma and inequality and challenging harmful social norms through open debate and dialogue is fundamental to tackling HIV and AIDS. Accordingly, this paper aims to locate AIDS communications initiatives within a broad framework that places critical emphasis upon working:

- In socio-cultural context.
- In partnership with communities and people living with and most affected by HIV and AIDS.
- At multiple levels (individual, community, national, international).
- To enhance the rights of individuals and communities affected by HIV and AIDS so that they can access health information, counselling and advice services, information communication technologies and other public information relevant to prevention, treatment, non-discrimination, stigma reduction and care.
- At policy and programme level to stimulate enabling environments in which people that are vulnerable to HIV are afforded greater levels of protection.

Policy framework for the DFID response to HIV and AIDS

1.4 These guidelines have been drawn up within the context of DFID's global HIV and AIDS reduction efforts (DFID 2004a; 2004b). DFID advocates a comprehensive response that integrates prevention, treatment and care and which emphasises that AIDS is not just a health issue, but also a social, cultural, political and economic one. This paper also takes into account the new challenges posed by the growing availability of treatment in developing

countries, supported by a number of international efforts such as WHO's '3 by 5' initiative, the President's Emergency Plan for AIDS Relief (PEPFAR), the World Bank's Multi-country AIDS Programme (MAP) and so on (see DFID 2004b, Annex 2 for an outline of current international treatment and care initiatives). It recognises the immediate need for a greater understanding of the role that communications can play in the scaling up of access to anti-retroviral treatment (ART).

1.5 Communication processes are fundamental to prevention, treatment and care. For example, Voluntary Counselling and Testing (VCT) represents a key mode of interpersonal communication through which people living with HIV are able to discuss the issues that affect them by connecting to networks of local peer educators or counsellors. Actions relating to prevention, treatment and care embrace different levels of communication activity, including the individual and family, the community, the national and international. Accordingly, within this paper an emphasis is placed on stimulating dialogue, the provision of useful and useable information and the building of skills at all levels (UNICEF 2002). This compliments the provision of services (e.g. VCT) and affordable commodities (condoms), as well as the formulation of policy and legal measures that help to protect the most vulnerable from HIV and AIDS (FHI 1999).

HIV and AIDS, poverty and vulnerability

1.6 In heavily affected countries such as Botswana, Cambodia and Zambia the AIDS epidemic is wiping out the development gains of the past two decades and will continue to have a severe impact upon future development prospects (UNDP 2001). For example, with an adult HIV prevalence rate of 35.4% recorded in 2002 Botswana is likely to experience a decline in per capita household income between 1998-2008 of 13% for the poorest households (UNAIDS 2000b). The human impact of HIV and AIDS is unequivocal. However, the causes and consequences of the epidemic are socially, culturally, economically and politically complex and locally dynamic, but nonetheless may reflect common criteria that are closely connected to the incidence of poverty (Melkote et al 2000). These include:

- Inequality (gender, race, age, etc.)
- Discrimination
- Insecure livelihoods and lack of social protection
- Poor service delivery (education, health, etc.)
- Poor governance
- Denial of rights
- Conflict

1.7 Such factors combine to make poor people, and especially poor women, particularly vulnerable to HIV infection as both a consequence of their disempowerment and greater exposure to risk that disempowerment brings (UNIFEM 2000). Women now account for nearly 50% of all people living with HIV and 57% in sub-Saharan Africa (UNAIDS 2004). Young people between the ages of 15 and 24 represent half of all new HIV infections worldwide. More than 6,000 people contract HIV every day (ibid). Though the relationship between socio-economic status and the epidemic is complex, wealthier people and those who are more skilled or educated are often better able to protect themselves, though they may also have greater opportunities for engaging in risky behaviour. For the poorest, available options and safe choices are severely constrained. Relevant public service information and health services may be unavailable or inaccessible and for those already living with HIV the cost of ART is likely to be prohibitive. Where treatment is available stigma and discrimination can negatively impact on its uptake and access to information about the benefits and limitations of ART may be unavailable (ibid). This limited range of choices makes it more likely that people will resort to survival strategies that make them vulnerable to HIV infection, for example, through sex work or migrant labour.

Box 1 My Future is My Choice: building life skills for HIV prevention in Namibia

In Namibia the Youth Health Development Programme, in conjunction with the ministries of youth, health and education, has been providing life skills education to children and young people aged between 10 and 18 years. The My Future is My Choice (MFMC) programme covers a range of issues that contribute to HIV prevention, including sexual health, safer sex, awareness of the risks of drug and alcohol abuse and peer pressure. The programme, which began in 1998, targets both in-school and out-of-school young people and aims to strengthen decision-making and negotiation skills through its participatory approach. The MFMC programme's ten two-hour sessions use young people who are trained as facilitators to provide peer education to in-school groups and to young people in the community. The approach uses a mix of formal education, peer education, games, participatory and skills-development sessions. Participants work through the programme and conclude by developing their own peer education action plan that they take to their own communities and implement. A study of the programme undertaken in 1998 found that participants were delaying sexual intercourse and using more condoms than non-participants (UNAIDS 2002a).

1.8 The impact of AIDS extends far beyond health and the health sector; it affects every sector whether it is education, social welfare, employment, planning, transport or defence. For example, a model jointly developed by UNAIDS and UNICEF has shown that in Zambia of the 1.7 million primary school students enrolled in 1999 some 56,000 lost a teacher to AIDS. In the previous year (1998) the number of teacher deaths in Zambia was equivalent to two-thirds of newly recruited and trained teachers (UNAIDS 2001). Since sectors are linked and mutually inter-dependent the impact of the epidemic spreads across these different sectors creating waves of repercussions throughout the system.

1.9 The emphasis placed on developing national AIDS reduction strategies in recent years and on collaboration and co-ordination between sectors reflects increased political commitment and allocation of resources, as well as a recognition of the cross-sectoral impact of AIDS. Naturally, the communication sector – the mass media, extension workers, community development personnel, community health workers and other health staff, unions and workers' associations and so on - have a key role to play in helping to create 'enabling environments' in which public information, communication and community outreach flourishes (DFID 2001a). People living with HIV and AIDS are playing an increasingly important role in creating this environment, through being open about their status, advocating for their greater involvement in policy making and in supporting each other through local, national and international networks (PANOS 2003).

1.10 Whilst evidence of the impact of HIV and AIDS communications interventions in particular has often highlighted failures to shift sexual or risk-taking behaviour amongst vulnerable groups, other indications are more positive. For example, there is evidence to suggest that exposure to mass media can be correlated against positive health practice and behaviour. In Namibia 61% of married women using contraceptives regularly use television, radio and print media. This compares with 25% of women who are exposed to two of these media, 20% who are exposed to just one and 12% to none (www.comminit.com).

Multi-pronged and co-ordinated strategies are more effective in reducing vulnerability than single 'one-off' approaches. Combining long-term efforts to reduce social exclusion (e.g. encouraging more girls to enter and stay in school), with more specific vulnerability reduction efforts can be mutually beneficial. The latter include building health policy around HIV and AIDS, building supportive environments, supporting community action and establishing young person-friendly health services (UNAIDS 2002: 27).

1.11 Developing linkages between formal and informal sectors is important. For example, where the burden of AIDS impacts upon households and household incomes, a corresponding decline in attendance at school often results as children are enlisted to bolster the household economy (UNAIDS 2002). Support to families burdened with AIDS to keep children in school, support to maintaining appropriate levels of trained teaching staff and an increase in informal education activities can all help to maintain high levels of information concerning the prevention, treatment and care.

1.12 In subsequent sections this paper addresses the recent UNAIDS communications framework for HIV and AIDS, existing behaviour change models and the complex interrelation between social, economic and political factors that drive HIV prevalence. Further, the paper will examine rights-based approaches to information, education and service delivery, before examining key areas of programme activity that can contribute to HIV prevention, harm reduction, AIDS treatment and care. Finally, process and evaluation issues relevant to communications interventions are addressed.

2 | Placing AIDS communication in context – learning from experience and facing new challenges

2.1 In recent years there has been a growing shift in the emphasis of AIDS communications interventions which is reflected in an explicit focus on the 'social' or 'community', rather than 'the individual' (UNAIDS 1999a; Panos 2002; Panos 2003). In turn, this reflects concern with past communications models that have targeted individual behaviour change without recognition of the social, cultural, economic, political and other environmental factors that constrain individual action (Airhihenbuwa and Obregon 2000). Early 'health belief' and 'reasoned action' models of behaviour change perceived of people as 'rational individuals' when it came to decision-making concerning the seriousness of health risks.

> Communication is central to prevention strategies aimed at influencing individual and social behaviour. Since there are so many variations in the contexts that determine behaviour, it is evident that communications approaches to HIV and AIDS prevention and care need to be re-evaluated. This is especially important when behavioural models are imported or adapted to the regions of the world that bear the main burden of the pandemic: Asia, Africa, Latin America and the Caribbean (UNAIDS 1999a: 17).

2.2 These 'psychological' models were widely adopted, especially where mass media were used to communicate aspects of risk and the benefits of better health. However, the ability of mass media (radio, television, film, press, etc.) and to a lesser extent participatory media (theatre, dance, certain types of video use, etc.) and peer approaches (counselling, buddying, etc.) to influence health-related behaviour by highlighting individual risk has broadly failed to bring about substantial change in the culturally and socially sensitive area of sexual behaviour (Panos 2003). This has resulted in the continual redefinition and refining of communications models, many of which have considerable overlap. A summary of popular communications and behaviour change approaches can be found In Box 2.

2.3 Recent models, such as behaviour change communication and behaviour change interventions (BCC/BCI) approaches quite rightly advocate a better understanding of individual sexual and risk-taking behaviour, but similarly, often fail to locate individuals within communities and environments that may constrain individual action and change (UNAIDS 1999b). Increasingly, those working with a behaviour change approach have sought to reposition the methodology towards a greater recognition of community ownership, community dialogue and structural impediments (such as gender inequality). A review of the methodology has suggested that BCC interventions can only be effective 'when combined with changes in broader environments that impact on people's ability to adopt and sustain a new behaviour' (Coombes 2001: 56). The often explicitly individual, western-oriented and theoretically driven approaches brought to communications interventions are not without their successes, but the reality for many poor people living in the developing world remains one of a greater sense of collectivity or coercion.

> Seeking to influence behaviour alone is insufficient if the underlying social factors that shape the behaviour remain unchallenged. Many communications and health promotion programmes proceed on the assumption that behaviour, alone, needs to be changed, when in reality, such change is unlikely to be sustainable without incurring some minimum of social change. This necessitates attention to social environmental contexts (UNAIDS 1999a: 21).

The UNAIDS framework and beyond

2.4 The UNAIDS Communications Framework for HIV and AIDS published in 1999 represents a significant milestone in AIDS communication. The framework (developed through a series of international workshops with communication practitioners) identified a number of weaknesses in past communication models, which included: a lack of focus on contextual factors; the assumptions that behaviour is based on rational

Box 2 **Communications models and terminology**

The use of language has been a critical factor in shaping our response to the AIDS epidemic. Confusing, inaccurate or judgmental terminology – such as using the terms 'AIDS' and 'HIV' as if they were interchangeable – leads to confusion and misunderstanding, in the same way that use of terms such as 'innocent', 'victim', 'carrier' or 'sufferer' can reinforce prejudice and be profoundly disempowering to those most directly affected by the epidemic. Within the field of communications, a number of different terms are currently in use, with different meanings and emphases, leading at times to a narrow focus on method over purpose and often participation. For the sake of clarity, commonly used terms used to describe certain communications models are summarised below.

Behaviour Change Communication (BCC) - refers to a programme or activity that is specifically designed to change or sustain the behaviour of individuals or social groups. BCC programmes use a variety of communication techniques, including targeted messages and interventions that cover a range of domains and levels (mass media, interpersonal, social marketing, training, community development, school curriculum, advocacy).

Behaviour Change Interventions (BCI) - refers to the various types and styles of interventions used in BCC programmes. Such interventions are often developed with the participation of target groups. By focusing on reducing risk behaviour, BCI can contribute to a reduction in vulnerability to HIV and AIDS.

Community Development - describes an approach to development work that is explicitly based on a set of core principles. These include: working in genuine partnership with communities in response to *their* agenda and concerns, advocating on behalf of minority or under-represented views, providing technical support in ways that build community capacity to sustain the project together with commitment to sustainable development, including long-term investment. A community development approach usually requires the concurrent support of planned organisational and policy development work, for example, through advocacy, lobbying, brokering and sharing of good practice.

Communications for Social Change (CFSC) - is an approach to using communications championed by The Rockefeller Foundation, which describes it as 'a process of public and private dialogue in which people themselves define who they are, what they want and need, and how to attain what they need to better their lives. Change is defined as the people themselves define it'.

Health Education - refers to a planned programme designed to increase knowledge (information), clarify attitudes and values and enhance skills (practice). As an educational model it places importance on rational decision-making and does not seek, specifically, to change behaviour.

Health Promotion - recognises that individuals are not always able to exercise their choices so a health promotion programme includes interventions designed to ensure that the environment (context) in which people live is made more enabling (through training, advocacy, provision of available and affordable resources and so on).

ICT (Information and Communication Technologies) - is a broad term describing a range of communications and computing media and includes e-mail, the Internet, satellite and digital communication, as well as terrestrial media such as television, radio, film and video.

IEC (Information, Education and Communication) - stresses the importance of information, through education, using a range of communication methods that are often top-down and instructive. It is a term that has much currency amongst southern governments and in certain contexts is used interchangeably with propaganda.

Multi-sectoral approach - describes a process through which several government departments, NGOs, community groups and the private sector are involved in joint planning and implementation of programmes. It recognises that to achieve objectives a multi-dimensional approach must be taken to reach all target groups in a variety of ways and through a variety of structures.

decision-making processes and that creating awareness through media campaigns will lead to behaviour change; as well as the application of optimistic strategies designed to trigger a once-in-a-lifetime behaviour (such as immunisation) to complex, life-long sexual behaviours (such as consistent condom use).

2.5 The UNAIDS framework reflected a refocusing of AIDS communication towards an emphasis on the role of people and communities as agents of their own change (this is reflected in the increasing focus on 'interpersonal and participatory communication' interventions, see Box 3.) It placed an emphasis on community empowerment and the importance of dialogue and debate in tackling the epidemic. It identified five 'contextual domains' that affect risk taking and health seeking behaviour, namely: government policy; socio-economic status; culture; gender; and spirituality.

2.6 What was significant about the framework was that it placed the individual firmly within a social and cultural environment, one that affects both individual choices and behaviours. The framework explored how communications and advocacy may influence the social and cultural environment to promote better choices and less risky behaviour and in the process define more effective HIV prevention, treatment and care interventions. Although this framework was widely acclaimed and built on the logic of mainstream health promotion approaches, its uptake has been limited. This perhaps highlights the difficulty in implementing complex and multi-layered communication programmes in resource-poor settings.

Box 3 **Interpersonal and participatory communications**

Interpersonal communications take many forms and include:

- One-to-one professional advice giving offered by health staff to patients or by teachers to students. It is essential that such interactions are informative and positive and allow space for questions.
- Peer education uses community role models, teachers and opinion leaders who are willing to be trained and who are committed to the goals of the programme to influence people within their own communities. Because they are not viewed as experts they are often trusted to a greater degree than medical counterparts.
- Mentoring and buddying follows a similar process and links individuals at risk or people living with HIV and AIDS who may be experiencing social exclusion and discrimination with mentors and buddies who support them.
- Voluntary counselling and testing (VCT) enables early detection of HIV and affords greater time for clinical care (where available) and support. Counselling helps people living with HIV and AIDS to come to terms with the personal and social implications of HIV and AIDS.

Participatory communication and learning is designed to engage communities and encourage dialogue, and in doing so, help them identify their immediate needs, impediments to their needs and solutions for realising their rights, access to goods and services and fair and equal treatment. Popular participatory communication and learning methods include:

- Community radio can be a powerful participatory medium both for disseminating information and for facilitating feedback and debate in a particular locality.
- Theatre that uses community members or actors to deal with HIV and AIDS-related issues, highlighting discrimination, stigmatisation, support and care, as well as a range of associated contextual and epidemiological factors.
- Role-playing that allows people in small public groups or in training sessions to put themselves in other people's shoes and act out a range of similar issues. This technique is useful for revealing latent discrimination.
- Video is used extensively to address issues of community conflict, discrimination and denial of rights. Video has been found to be an empowering tool when provided - with training - to groups who are in some way marginalised, such is often the case for people living with HIV and AIDS.
- Dance has similarly been used to empower the disadvantaged and marginalised.
- Oral testimony is useful in personalising the HIV and AIDS epidemic in bringing real voices and real faces to an issue that can be significantly dehumanised through stigmatisation and discrimination.

Box 4 Socio-cultural beliefs concerning HIV transmission in Cambodia

A recent ethnographic study of traditional healers and their patients in rural and urban areas of Cambodia suggests that many AIDS communications initiatives there are at cross-purposes with local notions of contagion. Sexually transmitted diseases were perceived as a confusing set of conditions – for example, the term *Crouching Mango illness* matched the description of Syphilis, with AIDS symptoms being perceived as a late phase of *Crouching Mango*. Women, particularly sex workers, were blamed for spreading STIs to men. In line with traditional views on gender it was perceived that only men could catch STIs and that they could not give them to women. Likewise, HIV was believed to originate in women, who were perceived as receptacles of 'bad' menstrual blood that could harbour the HIV 'germs'. It was believed that these 'germs' were caught through sexual secretions, via contact with bad menstrual blood, by squatting over the place where people with HIV, particularly women, had urinated or defecated (through steam or vapour rising from urine) or through people's sweat becoming intermingled. Consequently, condoms were deemed useless because they afforded little protection against the steam emanating from women's urine or sweat (Eastwood, Head & Skuse 2001).

HIV and AIDS, communication and human rights

2.7 Building on the UNAIDS framework and drawing on the lessons emerging at the country level UNICEF/UNAIDS (2002) have addressed the subject of communications, HIV and AIDS and human rights and suggest, like many others, that communication-based interventions targeting behaviour change can be ineffective. It is argued that this is because poor people are often unable to realise behaviour change because they are socially, culturally or economically constrained in the range of choices that they can make as a result of poverty and disempowerment. An alternative approach is suggested that advocates helping vulnerable people to 'claim their right to participation in decision-making, improved health and increased life opportunities' (UNICEF/UNAIDS 2002: 4). From this perspective communication and more broadly, access to information, are considered a 'right and a means (through community dialogue and advocacy) of claiming other rights' (OHCHR/UNAIDS 2002).

2.8 Organisations such as PANOS, The Rockefeller Foundation and The Communication Initiative support a community-based approach and identify some common threads running through the most successful communication responses to HIV and AIDS. These included 'a process of public and private dialogue through which people themselves define who they are, what they need and how to get what they need in order to improve their own lives' (www.changeproject.org/pubscompetenciesreport.pdf). Such responses tend to utilise 'dialogue that leads to collective problem identification, decision-making and community-based implementation of solutions to development issues' (ibid.). These criteria underpin the emerging Communication for Social Change approach that identifies community participation in and ownership of initiatives, as fundamental to effective communication.

2.9 Drawing upon the work of the Rockefeller Foundation and Communication for Social Change approach, UNICEF/UNAIDS suggest that development professionals need to 'pass ownership [of communications interventions] to community groups' and 'stop *doing* and start *facilitating*' (ibid.). This shift brings with it a reorientation in approach that places a critical emphasis on:

- Community dialogue rather than lecturing, and the use of community role models rather than the use of *stars* as role models.
- Social norms, policies and culture, rather than the individual.
- Community participation and ownership, rather than external *experts*.
- Peer and life-skills, rather than formal *education* from experts on epidemics.
- Indigenous models of effective communications, rather than imported western models.

2.10 Whilst both the UNICEF/UNAIDS rights-based approach to AIDS communication and Communication for Social Change approach locate ownership and change at community level, both are perhaps too critical of previous communications efforts and approaches that have sought to lessen the impact of HIV and AIDS, such as radio and television dramas (Tufte 2001). Though the approach suggests that community ownership and direction of initiatives is critical to shaping community debate and dialogue, both fail adequately to recognise the degree to which national media may stimulate *dialogue*. Similarly, both do not adequately address the range of macro-level, structural, environmental and policy factors and activities that can contribute to stimulating an environment in which community dialogue, information provision and education can flourish. Though in line with current thinking on community development, participation and empowerment, these approaches are still grappling with the thorny problem of 'going to scale' with what are essentially community based and highly localised communication responses.

Box 5 Islamic Medical Association of Uganda (IMAU) Family HIV Education and Prevention through Imams (FAEPTI) - Uganda

IMAU's project FAEPTI (Family AIDS Education and Prevention through Imams) helps Imams (mosque leaders) to incorporate accurate information about HIV prevention into their spiritual teachings by linking the teachings of the Qur'an with recommended risk-reduction behaviour. The religious leaders and teams of community volunteers are trained to provide education, basic counselling and motivation for behaviour change through individual home visits. IMAU believes that while mass information campaigns may be effective in changing the behaviour of some people, other individuals need a more personal approach. As well as teaching during home visits the Imams' teaching also occurs during congregational prayers and more intimate family ceremonies such as marriages, births and burials. A survey undertaken prior to the commencement of the programme to determine the knowledge, attitudes and behavioural practices related to safe sex and health seeking behaviour found that Muslim leaders and their communities needed further education regarding the risk factors that related specifically to some Muslim practices, such as polygamous marriage, ablution of the dead and circumcision, where non-sterile instruments were used. The survey determined the need to develop sensitive and appropriate messages regarding these practices. Imams and volunteers were then trained through workshops using a curriculum supplied by the Ministry of Health, but with special modifications made for the Muslim community based on the findings of the survey. A follow-up survey conducted two years later found that there had been significant increases in the accuracy of knowledge shared about HIV and AIDS in the project area. Community members also reported a significantly lower number of sexual partners and increased condom use (UNAIDS 1998).

AIDS treatment and the communication challenge

2.11 Despite problems associated with scaling up community-based approaches to AIDS communication the criteria upon with they are based are strongly reflected in new approaches to treatment. In July 2004 DFID published its HIV and AIDS treatment and care policy and this document reflected the growing consensus that 'treatment and care are essential parts of an effective and comprehensive response to AIDS' (DFID 2004b). At the international level, a huge increase in political will and financial resources for treatment, through WHO's '3 by 5', PEPFAR, MAP and the Global Fund for AIDS, TB and Malaria (GFATM), has meant that the availability of free ART is becoming a reality and basic right in many resource-poor settings and the AIDS response is shifting to accommodate this new development.

2.12 This emphasis on treatment and the roll-out of ART presents several key communication challenges (see Panos/WHO 2004). Anecdotal evidence suggests that treatment *may* increase risk-taking behaviour as people become well ('treatment optimism'). It will be important to ensure that individuals and communities are 'treatment literate', that prevention communication is closely integrated with treatment services and that treatment roll-out does not lead to a 're-medicalisation' of the way we think and talk about HIV and AIDS. Stigma and other social barriers may affect the level of uptake and adherence to ART regimens and it will be important to focus communication efforts on stigma reduction, particularly through promoting community dialogue involving people living with HIV and AIDS. In addition, where demand for treatment is high, it will be important to manage expectations and where possible ensure equity of access to ART. Communities affected by HIV and AIDS should be involved in decisions about the targeting and phasing-in of treatment. Open discussion and debate will be vital to ensure transparent decision-making (DFID 2004b).

2.13 Treatment also presents some communication opportunities. The roll-out of treatment provides an incentive for people to know their status and can increase demand for voluntary counselling and testing, the availability of which needs to be communicated. This in turn provides an important

entry point into care and support services, as well as prevention services for those who test both positive and negative (DFID 2004b). However, it is vital that treatment roll-out does not negatively impact on prevention efforts. The availability of treatment will require new communication approaches that integrate communication relating to VCT, treatment and prevention. This requires greater co-ordination of prevention and treatment communication programmes at the national level. It also requires that AIDS communication work uses multiple approaches and channels and is integrated into the delivery of essential services, including the social marketing of condoms, the prevention of mother to child transmission (PMTCT) programmes and counselling services. For more information on integrated approaches to HIV and AIDS communication see Box 6.

Box 6 **An integrated approach to HIV and AIDS communication**

Integration between treatment and prevention communication - As ART becomes more widely available, communication must be strategically linked to prevention through more harmonised and integrated approaches. Increased access to ART affords greater opportunities for enhanced prevention, including fresh incentives for testing. A lack of integration and co-ordination could lead to complacency as well as increased risk behaviour. Many of the social issues linked to prevention communication, such as exclusion, poverty and gender remain pertinent to equitable access to treatment.

Integration of HIV and AIDS communication programming among various partners - This entails development of a strong partnership and information-sharing network around AIDS communication within countries, comprising many different voices including National AIDS Coordinating Authorities (NACS), the UN, NGOs, community-based organisations (CBOs), faith-based organisations (FBOs), people living with HIV and AIDS and the private sector. AIDS communication in most high-burden countries has been insufficiently integrated with little emphasis on long-term sustainable results. The availability of ART risks fragmenting country-level communication even further. The proliferation of HIV and AIDS programmes, such as testing, counselling and ART roll-out, coupled with new sources of funding, means it is increasingly important for organisations to act in synergy. Strong partnership networks around AIDS communication will ensure that countries have the capacity to reap the maximum benefit from the development of well-conceived strategies.

Integration of communication into HIV and AIDS service delivery - ART roll-out must be accompanied by effective communication programming that creates awareness and understanding of treatment in communities and promotes treatment literacy among patients. Community readiness – a key factor in a successful scale-up of ART – will be generated and supported by effective locally based communication.

Integration between various health communication methodologies - A successful communication strategy comprises a variety of approaches, including behaviour change communication, social marketing and the use of mass media. At the same time, it needs to ensure that basic communication principles, such as local ownership, strategic targeted interventions, dialogue and debate, are respected. Providing a space for community dialogue needs to be emphasised. This can prove an effective means of addressing the stigma and denial that surround HIV and AIDS in so many communities.

Adapted from: PANOS/WHO 2004. Unpublished paper 'HIV/AIDS Communication and Treatment Scale-up: issues and challenges emerging from the Integrated AIDS Communication Meeting', April 2004. See also FHI 2003.

Guinea Bissau
DJ at a local radio station, presenting
a programme about HIV and AIDS.

3 A DFID approach to AIDS communication

3.1 Three broad fields emerge from the UNAIDS framework, the Communication for Social Change agenda and the UNAIDS/OHCHR HIV-related human rights guidelines that are broadly supportive of: (i) participation and empowerment at an individual and community level; (ii) the realisation of rights; and (iii) DFID's own HIV and AIDS country programme work. These are:

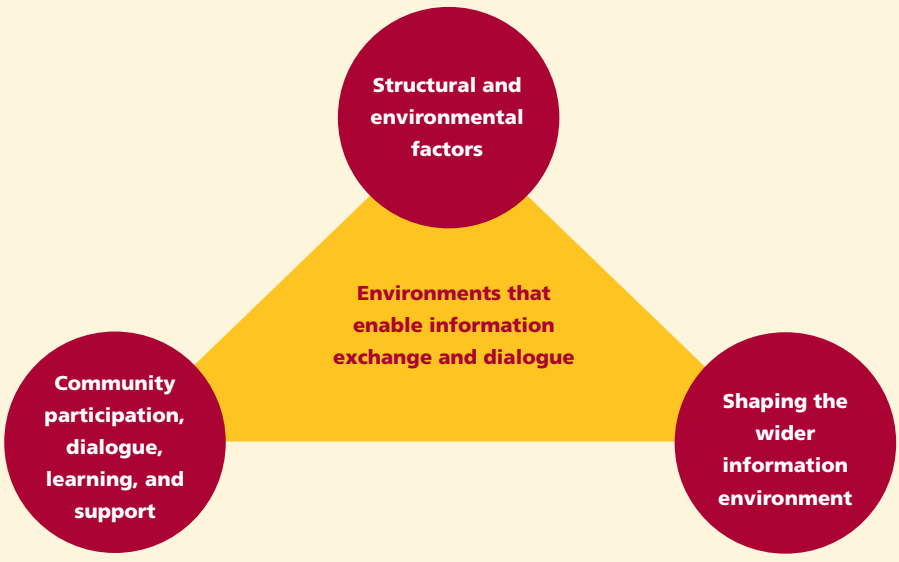
- Structural and environmental factors.
- Shaping the wider information environment.
- Community participation, dialogue, learning and support.

These fields provide a useful set of categories under which the various AIDS communication interventions in the areas of prevention, treatment and care may be placed. Whilst this paper examines broad responses to HIV and AIDS and the role that communications can play within them, it is useful, in programme terms, to identify the types of activities that fall into these categories. This is done at the end of each section.

Structural and environmental factors

3.2 Advocacy work and policy change play a fundamental role in shaping the environment in which HIV and AIDS-related rights to information, services and care are realised or denied. Strong and informed political commitment and leadership at the highest level is critical to addressing the epidemic and therefore the development community – donors, NGOs, civil society organisations (CSOs), etc. – all have a role to play in lobbying and advocating for change that supports and protects those who are most vulnerable. For example, communication and advocacy has played a key role in making anti-retroviral therapy (ART) more affordable and accessible in many parts of the world. Combined advocacy activities by northern and southern-based organisations have raised the issue of the high cost of ART. Their demand, that negotiations around reducing costs be placed on policy agendas of international agencies, governments and the pharmaceutical industry have led both to individual companies changing pricing

Figure 1 **Three linked HIV and AIDS-relevant communication fields**



structures in favour of pro-poor policies and to a better understanding of how the World Trade Organisation agreements can be used by national governments to enable generic producers of anti-retroviral drugs to produce lower-cost versions of the drugs. At the same time, advocacy has called for increased resources to be made available to finance the supply of ART. This strategy is now bearing fruit in some countries such as South Africa and China.

3.3 The politicised nature of treatment in some contexts means there is considerable energy that can be channelled at political leaders and legislators to advocate for pro-poor treatment policies. National forums for social participation, social movements, community-based organisation and groups that are run by and support people living with HIV and AIDS groups can all be supported in their efforts to reduce stigma, promote demand for and adherence to treatments. All help to bring the voices of the poor and marginalised to the forefront of the treatment debate at the national and international level (PANOS 2003). It is important, therefore, that appropriate governance structures are in place that allow for this, by, for example, giving space to civil society organisations to scrutinise and inform government policy. In addition, how the media is regulated and how the state relates to the citizen are important factors in determining the possibilities for open discussions around HIV, sex and sexuality. Where possible, responses should support civil society and media organisations in their roles as facilitators of communication processes, as well as disseminators of information. Such processes include promoting community discussion and building channels of communication between communities and government, so that local action can be supported with appropriate information, service delivery and policy.

3.4 Understanding the role of media in the context of HIV and AIDS is important. A free and vibrant media can disseminate accurate information, provide a space for public debate, challenge government policy as well as negative social norms, and has the potential to reach and give voice to the poor and marginalised. Even in difficult environments where the activities of the media are restricted and politically biased it can still play an important role in prevention and awareness raising. Similarly, National AIDS Coordinating Authorities (NACs) have a critical role to play in developing an active dialogue with communication stakeholders to help define:

- Media and communications policy that encourages the media (including state-controlled media) to be as active as possible in its response to the epidemic.
- Education policy, curricula and learning materials that are responsive to the information and life-skills needs of vulnerable children and young people and which place an emphasis on cross-sectoral working and co-operation.

Examples of what DFID can do at the structural and environmental level can be found in Box 7.

Shaping the public information environment

3.5 Shaping the public information environment in order to facilitate dialogue and debate on HIV and AIDS at multiple levels is important if HIV-related rights, better services and greater government transparency and accountability are to be realised. Public debate and dialogue is stimulated in many ways – for example, through networking, the dissemination of knowledge and sharing of best practice, the incorporation of HIV and AIDS-related issues into print and mass media and the media holding governments accountable for their response to the epidemic.

3.6 Civil society organisations and the media have a central role to play in this response. The media in particular is an important source of information about HIV and AIDS and is also an effective means for stimulating debate on the epidemic and challenging social norms through often entertaining and informative formats (see DFID 2004c on the various media formats used in health communications). Civil society organisations play an important role in advocating for government action and in supporting local communication and support

Box 7 **What can DFID do at the structural and environmental level?**

What DFID can do internally

Establish strong links between work on AIDS communication and work with other theme groups in DFID.

Support research that takes a broader view of AIDS communication and its impact.

What DFID can do at country level

Support the 'Three Ones' principle of developing an agreed national HIV and AIDS action framework, one National AIDS Coordinating Authority (NAC) and one agreed country-level monitoring and evaluation system.

Work with NACs to enhance the public information environment through media legislation designed to increase the transparency and accountability of government practice and increase and enhance the quality of the coverage of HIV and AIDS by state and commercial broadcasters.

Encourage advocacy work with political leaders to raise awareness of the scale of the HIV and AIDS problem and advocate for increased government support in all sectors. These activities seek to influence decision makers through actions such as hosting events and providing briefings and through forums that encourage open public debate (e.g. phone-ins). The involvement of people living with HIV and AIDS in such advocacy work is critical to its impact.

Work with partner governments to develop pro-poor ICT policy and deregulation of the media and telecommunications sectors that allows poor people fair and equal access to low-cost and appropriate ICTs.

Support AIDS communication efforts that are co-ordinated with others and which are linked, where possible, to national AIDS communication strategies.

Ensure that DFID-funded communication activities are linked to service delivery and commodity availability. Facilitate the availability of products and services such as palliative care and drugs, condoms, counselling, voluntary testing and so on, using mechanisms such as advertising and the social marketing of affordable commodities.

What DFID can do at global level

Highlight the links between poverty and vulnerability and stress the actions that can be taken to address them.

Encourage and advocate for broad approaches to communications that recognise and give voice to a diversity of perspectives.

Box 8 **What can DFID do to help shape the broad information environment?**

What DFID can do internally

HIV mainstreaming training for all staff.

Build evidence base around communication approaches and HIV and AIDS, particularly in relation to monitoring and evaluation.

Capture good practice in AIDS communication across DFID and internationally.

Use DFID web sites to disseminate evidence of successful approaches to AIDS communication, including case studies.

What DFID can do at country level

Advocate for the development of innovative schools' curriculum materials that build life skills for vulnerable children and young people.

Strengthen schools to become active community centres, media centres and information hubs that provide a service to both school children and the wider community.

Network and share models of knowledge and good practice in communications at multiple levels through enhanced civil society co-ordination, collaboration and policy dialogue.

Promote the use of mass media to increase the quantity of information in the public domain, its quality and its relevance, as well as the use of specific genres of print and mass media to increase community dialogue around HIV and AIDS.

Stimulate the analysis of AIDS communication initiatives at country level.

Encourage and facilitate wider involvement of representatives from a range of diverse perspectives in discussions on national policy. This should involve ensuring that the voices of those living with and affected by HIV and AIDS are heard.

Encourage forums for public debate and dialogue using a wide range of media - from mass media to popular and culturally relevant media - to enable divergent voices to be expressed.

What DFID can do at global level

Work in partnership with others to develop a set of internationally agreed indicators to measure the impact of AIDS communication approaches.

Disseminate findings of DFID research programmes as they relate to AIDS communications.

Engage in existing networks on AIDS and communication issues to contribute to current debates and approaches.

Set up regional learning networks across DFID relating to AIDS communication to share ideas and experiences.

Promote the use of information and analysis that has been generated by those affected by HIV and AIDS at the international level.

networks. However, it is important to recognise that these organisations often do not have the capacity (in particular in terms of personnel) to implement multi-layered and complex communication strategies. DFID programmes should therefore link any strategies that aim to increase access to information to efforts to build this capacity.

3.7 There is a clear need for joint learning and knowledge sharing between policy makers, civil society organisations and communities about what works and what does not. In particular it is important to bring the voices of those most affected by HIV and AIDS into policy discussions and public debate. Responses should support improving access to information and good practice, as well as strengthening HIV networks as a means of sharing experiences. Responses should also promote mass media efforts that are linked to and increase community dialogue on HIV and AIDS, where possible.

3.8 Similarly, increasing community access to information and communication technologies (ICTs) is critical to shaping the broader public information environment. For example, schools, as community-based institutions, represent ideal places for both school and non-school populations to engage in group radio listening, television viewing, Internet use and a host of peer education and community-based activities. They are increasingly being considered as logical sites for community media centres (see http://www.unesco.org/webworld/cmc). ICTs can expose children and young people to different learning experiences that are both fun and informative. Further, they can help in the targeting of non-school populations of young people and drive changes to the delivery of education itself, i.e. through distance or community and informal learning (UNESCO 2002a; 2002b).

Examples of what DFID can do to help shape the public information environment can be found in Box 8.

Community participation and dialogue

3.9 Contemporary approaches to AIDS communication recognise the need to increase and facilitate community participation in and ownership of initiatives. They also place greater emphasis on the importance of open, public debate and inclusive policy development involving those affected by HIV and AIDS. Understanding the community's information needs, requirements for care and support, poor people's success at accessing treatment and services and the extent to which people living with HIV and AIDS within communities are discriminated against are all critical questions that can be addressed through participatory processes. This is particularly important for developing communication interventions that meet the needs and concerns identified by community members themselves.

3.10 Whilst mass media has a clear role to play in raising awareness of HIV and AIDS from community to national level, increasing attention is now being paid to participatory communications, interpersonal communications and other face-to-face interactions, as well as peer education techniques that address the sensitive issue of HIV and AIDS from within local realities at community level. In Brazil, people living with HIV and AIDS, together with other civil society organisations, have played a key role in community mobilisation as well as in advocating for the national policy of universal free provision of ART (WHO 2003). In South Africa, civil society organisations such as the Treatment Action Campaign have played an important role in educating communities about HIV and AIDS and treatment issues. Preparing communities in this way has been critical for both uptake of, and adherence to, treatment by patients attending the MSF Khayelitsha clinics in Cape Town, South Africa (ibid.).

Examples of what DFID can do to facilitate community participation and dialogue on HIV and AIDS can be found in Box 9 overleaf.

Box 9 **What can DFID do to facilitate community participation and dialogue?**

What DFID can do internally

Training for staff on good practice in participatory approaches to communication.

What DFID can do at country level

Support activities that identify community issues (poverty, behavioural, rights, beliefs, cultural practices etc.) and opinion through participatory research methods.

Support activities that build community involvement – through one-to-one and group support (e.g. peer education and outreach to disenfranchised groups), joint project development (i.e. in a schools setting) and collaboration (i.e. linking to community health services) and professional development opportunities (i.e. diversity training for staff).

Work with civil society groups to enhance their HIV networks.

Promote interpersonal communication approaches that take the issue of HIV and AIDS to the individuals and the community in a direct way. These create opportunities for young people and others vulnerable to HIV and AIDS to discuss the epidemic, its implications, how to prevent it and how to care for and support People living with HIV and AIDS.

Support the creation of communication channels that provide forums for discussion, at least partially free from government and commercial constraints (such as community radio), appropriate to the local community, and sensitive to cultural diversity.

Promote and support the training of new communicators in participatory and social change communication approaches.

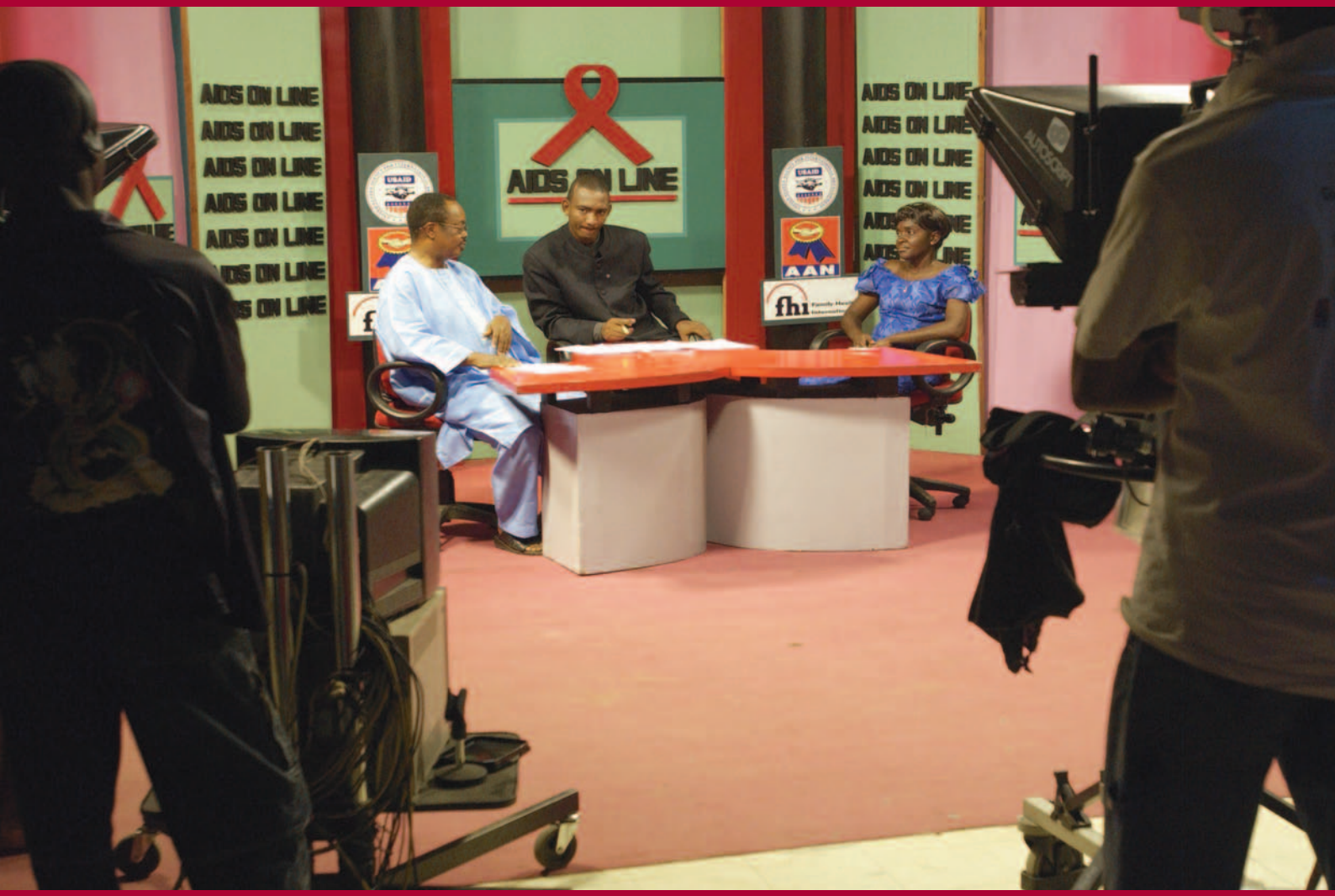
Promote activities that bring together media and community efforts to improve the provision of treatments.

What DFID can do at global level

Advocate policy changes that encourage governments to fulfil their human rights obligations to citizens and allow people living with HIV and AIDS to have meaningful influence.

Provide leadership and platforms for developing thinking about 'enabling communication environments'.

Create opportunities for increased engagement by HIV and AIDS civil society organisations in international policy dialogue on HIV and AIDS issues.



Nigeria Lagos
Mohammed Farrouk (centre), who is HIV positive, hosts the 'AIDS On Line' television show with guests Dr. Charles Okanny (left) and Abigael Obeten. The program appears live on government owned television stations weekly to educate and inform the public about HIV and AIDS.

4 Communication planning and process

4.1 Increasingly, communication interventions are seen to be process-focused (i.e. dealing with more than a single event or set of activities and dwelling as much on how things are done as what is done), participatory (rather than top-down, one-way, and 'outsider-driven') and change-oriented (whether this relates to knowledge, attitudes or behaviours). Approaches to communication vary in the extent to which they consider and address the socio-economic, cultural and spiritual dimensions of people's lives. However, it is recognised that stand-alone communication activities are often not effective and that a combination of complementary activities have a greater potential to contribute to the realisation of human rights.

4.2 Previous approaches to AIDS communication have often worked with a 'component' mentality that has not adequately recognised the considerable role that informal education and media such as radio, television, video, participatory theatre, song, press and posters can play (see www.comminit.com/hotfive_joserimon.html). DFID advocates a closer relationship between AIDS communication initiatives under which activities in formal education, social marketing, radio, TV, telecommunications, community mobilisation, outreach and counselling actively link with each other. This trend reflects the move away from traditional top-down and didactic information campaigns towards a multi-method approach that recognises the diversity and voice of people involved at all levels (ibid.).

4.3 There is a need to ensure that, where possible, communication activities at the national level are co-ordinated and strategic. AIDS communication within most high-burden countries has been fragmented, ad hoc and implemented outside the framework of a comprehensive country-level response to HIV and AIDS (PANOS/WHO 2004). Treatment availability threatens to fragment country-level communications further, as does the increasing in-flow of resources from a variety of sources. To ensure that the communication response is strategic and that the maximum impact is achieved with the available resources, DFID should promote the development of a strong partnership and network around AIDS communication at national level that will ensure countries have the capacity to develop an 'at-scale' and locally owned communication strategy.

Box 10 **Programme planning sequence**

Assessment of current situation with communities, addressing:

- Existing practices, knowledge and resources
- The policy background and social context

Identifying intermediate factors such as:

- Policy Frameworks
- Significant beliefs affecting behaviour
- Basic needs affecting behaviour
- Knowledge and understanding
- Specific skills

Developing programme(s) targeted at different levels:

- Strengthening the 'enabling environments' through policy development and capacity building
- Dealing directly with people to address specific circumstances and to consider likely consequences
- Based on realistic objectives (often directly related to intermediate factors rather than behaviour or epidemiological change)

Evaluation:

- Against programme objectives
- Against guiding principles

AIDS communication: good practice;

4.4 Good practice in communication interventions reinforces what has long been recognised as effective: a mix of methods that are sustained over time, mutually reinforcing, culturally relevant - where possible, drawing upon easily identifiable role-models – and with appropriate use of relevant technologies. Such methods of communication should:

- Be built upon a strong evidence base of behavioural or skills requirements or clear research hypothesis.
- Be sensitive to the specific socio-economic cultural, and communicative circumstances, recognising differences in gender, age, status, ability and so on.

Box 11 Health education and promotion: creating better access for girls and reducing the risk of HIV

A DFID-funded study (Barnett et al. 1995) undertaken on the state of health education in developing countries' schools found that health education was poorly integrated into curricula and that teaching methods were extremely didactic. However, evidence of better practice was found in Uganda where more participatory and inclusive approaches to health education were found. Also, Uganda was the only country in the multi-country study to have formal teacher training relating to health education. The study found that schools tended to lack latrines (a key factor in the non-attendance of girls) or clean drinking water and that despite children suffering poor nutrition, little was done to attempt to rectify this problem or reach children with basic health services. However, the study did identify shifting attitudes to student health, which have subsequently come to the fore in health and education policy and planning. For example, UNICEF is currently working with the Kenyan government to address some of the barriers preventing girls from attending school. Under the African Girls' Education Initiative, UNICEF is supporting the Kenyan government's efforts to develop: (i) a specific girls' education policy; (ii) curricula materials for students and teachers on HIV and AIDS; and (iii) life skills approaches to education in areas of high HIV prevalence. The programme to date has addressed issues relating to water and sanitation in schools, has institutionalised HIV and AIDS education within the curriculum and has sought to improve learning environments by increasing the security of girls attending school (http://www.unicef.org/)

- Use a mutually reinforcing mix of methods.
- Be sustained over a sufficient period to demonstrate (realistic) results - for example, allowing time for establishing relationships with beneficiaries and stakeholders - and build capacity and skills at all levels.
- Reflect local circumstances in terms of relevant structures, learning culture, channels and systems of communication. Locally focused efforts should be complemented with higher-level initiatives designed to build awareness and provide support.

Box 12 Wanchai Nightclub Outreach Programme - Hong Kong, China

AIDS Concern and Action for Reach Out devised a programme to reach out to Filipino women working in the commercial sex industry in Hong Kong nightclubs. With the consent of nightclub owners, clubs were regularly visited. Many of the women were found to be unclear about the risks of HIV transmission and ill-informed regarding the free medical care available to them in Hong Kong under the terms of their 'entertainer's visa'. Via counselling, information dissemination and making condoms available in nightclubs a network of 13 clubs serviced by the programme had been established by 1998. All 13 clubs took part in the 1998 World AIDS Condom Coaster Campaign, which promoted HIV awareness and safer sex directly beneath the beer glasses of these sex workers' clients (www.unaids.org).

- Enlist support of religious, political and social leadership as early as possible in order to create a more favourable environment conducive to change.
- Be clearly linked to relevant services such as health and education and to the overall process of a multi-sectoral programme - rather than being perceived as independent (health-sector) products.

4.5 In summary, good AIDS communication initiatives link to policy and advocacy interventions, they understand risk groups, skills, informational and educational needs, media preferences, information exclusion (often based on gender) and the social,

economic, spiritual and cultural dynamics of the epidemic. They also include and work with a range of organisations – from mass media to CSOs - to help facilitate dialogue around HIV and AIDS.

Box 13 Stepping Stones training packageon HIV and AIDS, gender issues, communication and relationship skills

Since it began in Uganda in 1995 *Stepping Stones* has been in regular use in at least 20 countries in Africa, Asia and beyond. *Stepping Stones* grew out of awareness of the limitations of more traditional approaches to education on HIV and the need to address the vulnerability of women and young people – as well as men - in relation to decision-making about sexual behaviour. It is based upon the assumptions that:

- The best solutions are those developed by people themselves.
- Men and women each need private time and space with their peers to explore their own needs and concerns about relationships and sexual health.
- Behaviour change is much more likely to be effective and sustained if the whole community is involved.

A comprehensive manual provides detailed guidance for facilitators who work in partnership with ordinary members of local communities in implementing a series of participatory, structured workshops that are both gender and age sensitive. Instead of concentrating on individuals or segregated 'risk groups', *Stepping Stones* works in groups of peers of the same gender and similar age (younger women, younger men, older women and older men) drawn from the whole community. The groups work separately much of the time so they have a safe and supportive space for talking about intimate issues, periodically meeting together to share insights. Throughout, participatory methods are used, including songs, games and role-playing, which are enjoyable and enlightening as well as serious and profound. The process builds on people's own experiences, needs and priorities. It enables exploration and negotiation, which are essential for sustained behaviour change by individuals and communities (Wellbourn 1995).

Evaluating communication interventions

4.6 Clearly, *how* things are done in communication interventions and *with who* are as important as *what* is done. As our approach to communication in the field of HIV and AIDS shifts to community skills-building, facilitation and dialogue, so too should the criteria by which the success of such interventions are measured (UNICEF/UNAIDS 2002). It is unrealistic to expect single activities in themselves – such as mass media campaigns, leaflets, drama or formal education – to produce changes in behaviour in isolation from broader interventions that address, for example, policy, poverty, human rights (including stigma and discrimination) and service or commodity provision (such as sexual health services, counselling, the social marketing of condoms and treatment). In turn, this raises questions as to what might constitute realistic and useful measurements of the progress and success of individual components of AIDS communication programmes.

4.7 In recognition of the need for more subtle measures, The PANOS Institute (2002), UNAIDS (1999a) Rockefeller Foundation (1999), Communication Initiative and UNICEF have been instrumental in defining new sets of indicators that are consistent with a focus on community dialogue and broader social change, rather than individual behaviour. The Rockefeller Foundation has facilitated work in this field, specifically focusing on informal communication activities which highlight the need for indicators that measure both process and progress and which help to direct the nature of the interventions themselves by providing continuous feedback. They highlight the following key areas that reflect programme and policy work that maintains the theme of facilitating and enhancing dialogue, rights, participation and empowerment:

- Expanded public and private dialogue and debate.
- Increased accuracy of the information that people share in the dialogue and debate.
- The means available that enable people and communities to add their voices to debate and dialogue.

- An increased leadership and agenda-setting role by disadvantaged people on issues of concern that resonate with the major issues of interest to people's everyday interests.
- Links between people and groups with similar interests who might otherwise not be in contact.

These and additional impact indicators developed by the aforementioned organisations can be applied to the three communication-related fields that have been defined in this paper. They emphasise community dialogue and the creation of information-rich environments above individual behaviour change. The indicators in Box 14 highlight intermediary goals that, in combination with other programme components such as condom availability, formal education, health service delivery and so on, contribute to the higher-level goals of a reduction in risk-taking sexual behaviour, the realisation of HIV and AIDS-related human rights, the participation and empowerment of communities affected by HIV and AIDS and lower overall prevalence rates.

DFID desk officers and advisers should expect to see the approach to AIDS communication initiatives highlighted in this paper reflected in the indicators and logical frameworks of programme and project proposals and organisational principles of the partners with whom DFID works.

Box 14 **Evaluation indicators for the impact of AIDS communications**

Indicators of structural and environmental change communication:

- Evidence of the impact of advocacy work reflected in citations, references and responses in grey literature, publications of governments, NGOs and civil society, as well as invitations to speak, present or broadcast.
- Evidence of direct policy actions or changes.
- Evidence of media and ICT deregulation and legislation.
- Multi-sectoral involvements identifiable at the national level for HIV prevention, AIDS care and support.

Indicators of public information environment communication:

- Expanded public and private dialogue and debate on AIDS issues.
- Identifiable increases in family discussion; discussion among friends; discussion in community gatherings; coverage and discussion in news media; problem-solving dialogue; focus and discussion in entertainment media; and debate and dialogue in the political process.
- Increased accuracy of the information that people share in the dialogue/debate.
- Evidence of increased media coverage of HIV and AIDS.
- Evidence of increased government transparency and accountability resulting from political commitment to HIV and AIDS and civil society/media watchdogs.

Indicators of community participation and dialogue communication:

- Increased recognition and knowledge of issues among target audience, increased accuracy of information.
- Increased negotiation and life skills evident amongst young people and children.
- Community's cultural activities (sports, folk media, festivals, celebrations, songs, etc) engage with HIV and AIDS issues.
- New community-based programmes and initiatives have been launched to address HIV prevention, AIDS care and support.
- Religious organisations and spiritual leaders are involved in prevention, care and support programmes.
- The people centrally affected by HIV and AIDS voice their perspective in the debate and dialogue.
- Individuals or groups seek further information or take action as a result of AIDS communications interventions.
- New coalitions and alliances have emerged among community organisations to address HIV and AIDS issues.
- Improved inclusion of those most affected by HIV and AIDS and their concerns in policy-making forums.
- Increased leadership roles for people disadvantaged by HIV and AIDS.
- Community members have collectively taken decisions or passed resolutions about tackling HIV and AIDS.

India Calcutta
AIDS education for community
health volunteers.

5 Knowledge gaps and research priorities

5.1 A large amount of research has been undertaken in the field of AIDS and communication. The UNAIDS (1999c) annotated bibliography *Communications programming for HIV and AIDS* provides an overview of material that is broken down into a range of critical themes. Themes seemingly not well covered in the available research and which can usefully be considered as representing an agenda for future work include assessment of:

- The synergies evident between formal and informal health education and promotion initiatives. For example, what are the most appropriate and cost-effective mixes of communication channels and interpersonal/peer approaches in HIV prevention campaigns?
- What people already do in terms of their ability to cope with the burden of HIV and AIDS and especially caring? How are communication activities supporting these strategies? Do the differing levels of access to information and communications technologies enjoyed by each gender have an impact on coping and care regimes? How can existing coping strategies be strengthened and opportunities maximised for people to gain exposure to appropriate and targeted communications materials?
- The relationships and bodies that need to be established across different sectors in order to fully support an integrated health education approach inclusive of school-based populations and the broader at-risk population. How, for example, can ministries of education and health encourage closer co-operation between the broad range of informal or mass communication initiatives in HIV prevention and schools-based health education? How best can curricula and skills-based learning be used alongside innovative media-based approaches to the mutual benefit of the vulnerable?
- How to formulate policies that provide environments conducive to better ICT access for the poor, students and teachers; to encourage secure, inclusive and health-promoting schools; and to realise rights to information, expression and education. For example, how can improved ICT infrastructure and access be equitably delivered to poor communities?
- Support mechanisms to aid community participation in both formal education curricula and informal communication for HIV prevention design, planning and implementation processes. For example, how can capacity be built at national and local levels to assist communities with assessing information needs? How can such assessment guide local initiatives?
- The role of communications and civil society involvement in the scaling up of anti-retroviral therapy. In particular, how it relates to access, adherence and risk behaviour.

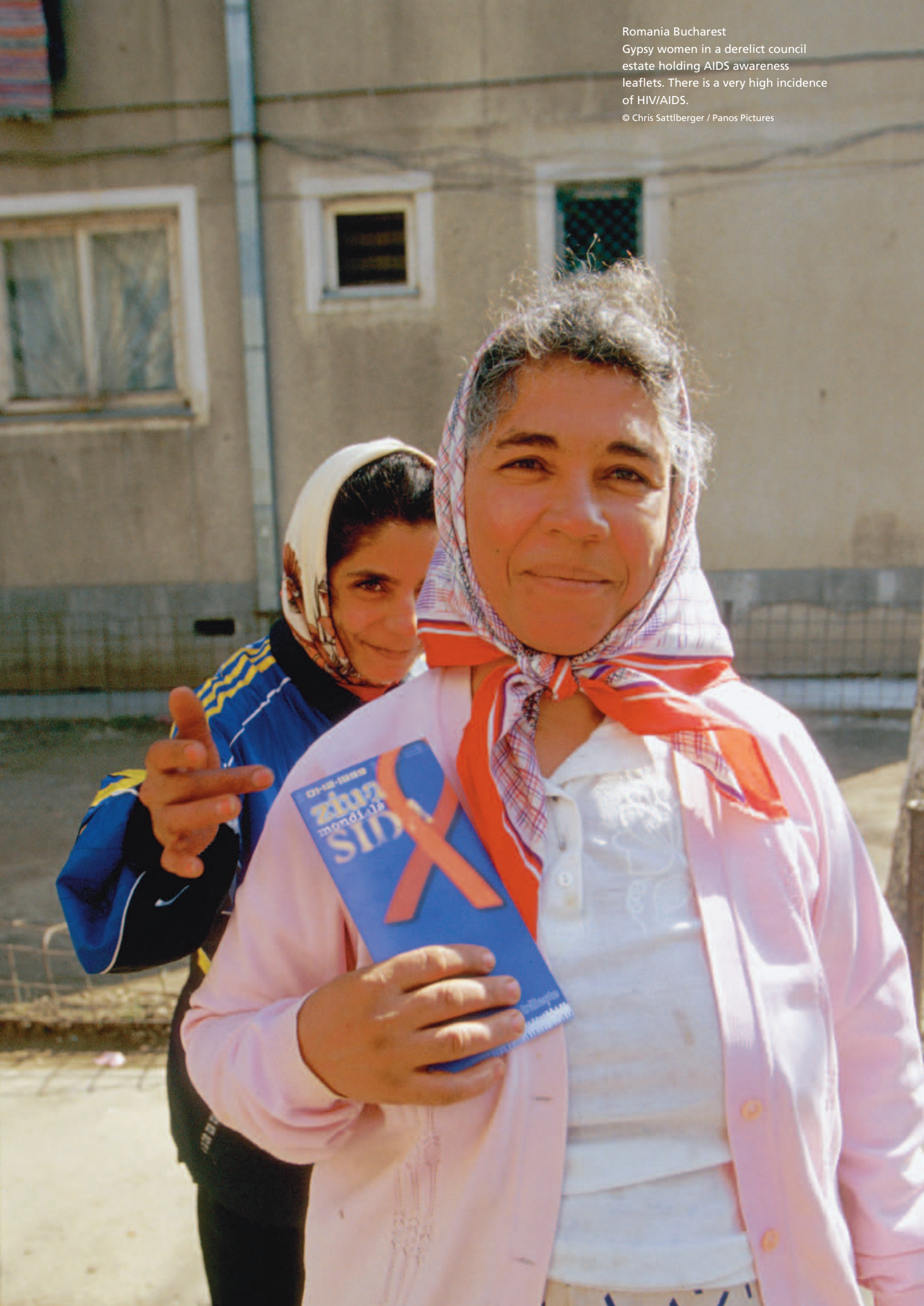
6 Conclusion: a DFID response

6.1 This paper has sought to highlight a range of communication approaches that can help build a more positive environment for HIV and AIDS prevention, risk reduction, access to treatment and services, information, care options and stigma reduction. It has also highlighted issues of process and evaluation that will help DFID desk officers, advisers and other development agencies to take informed decisions about the project and programme activities they may wish to pursue.

6.2 Consistent with its broader HIV and AIDS strategy, DFID's role in relation to communications and the HIV and AIDS epidemic is multi-faceted. It includes work within the organisation itself as well as work undertaken at community, country and global levels. Taking advantage of recent developments in the area of communication - both in terms of improved understanding of the impact of communication in relation to the epidemic and in terms of increasing access to and use of all forms of information communication technologies in the south – DFID is committed to matching its response to the epidemic to the scale of the challenge it presents.

As DFID desk officers there are five things you can begin today:

- **Review your current support to AIDS communication activities. Do your actions support a complimentary range of interventions in prevention, treatment and care?**
- **Begin mapping work to identify country-based communication activities to which DFID's HIV and AIDS programmes can be linked and from whom further technical advice may be sought.**
- **Think about the role of AIDS communication programmes in the context of your work with the Global Fund for AIDS, Tuberculosis and Malaria.**
- **Work with the NAC to ensue that DFID-funded AIDS communication programmes are linked to others, and that best practice and experience is shared and disseminated.**
- **Make contact with DFID staff working in this field, especially in the Information and Communication for Development Team. They are Fiona Power and Nicola Woods and can be contacted at ICD@dfid.gov.uk**



Romania Bucharest
Gypsy women in a derelict council estate holding AIDS awareness leaflets. There is a very high incidence of HIV/AIDS.

Appendix 1

Communication and HIV and AIDS rapid reference guide

AIDS communications programming objectives recognise	• A shift away from the often unattainable and unrealistic goals for behaviour change that are set at project or programme level, towards a stronger emphasis on rights to education and information, community participation and dialogue. • An integration, where possible, of prevention and treatment communications.
AIDS communications planning principles recognise	• Socio-cultural context. • Social norms, policies and culture, rather than the individual. • Participation with communities and people living with HIV and AIDS. • Community dialogue and role models, rather than didactic messages and the use of *stars* as role models. • Community participation and ownership, rather than external *experts*. • Indigenous models of communications best practice, rather than imported western models • All aspects of HIV and AIDS prevention, treatment and care. • Peer- and life-skills, rather than formal epidemiological *education*. • Multiple levels (individual, community, national, international). • The need to enhance the rights of individuals and communities affected by HIV and AIDS so that they can access health education, counselling and advice services, information communication technologies and other public information relevant to treatment and prevention, non-discrimination, stigma reduction and care. • The need at policy and programme level to stimulate enabling environments in which people who are vulnerable to HIV and AIDS are afforded greater levels of protection.
Three strategic AIDS communication fields emerge	• Structural and environmental factors. • Shaping the wider information environment. • Community participation, dialogue, learning and support.
Communications and HIV and AIDS programming principles recognise the need to	• Be built upon a strong evidence base of behavioural or skills requirements or clear research hypothesis. • Be sensitive to the specific socio-economic, cultural and communicative circumstances, recognising differences in gender, age, status, ability and so on. • Use a mutually reinforcing, mix of methods. • Be sustained over a sufficient period to demonstrate (realistic) results - for example, allowing time for establishing relationships with beneficiaries and stakeholders - and build capacity and skills at all levels. • Reflect local circumstances in terms of relevant structures, learning culture, channels and systems of communication. Locally focused efforts should be complemented with higher level-oriented initiatives designed to build awareness and provide support. • Enlist support of religious, political and social leadership as early as possible in order to create a more favourable climate. • Be clearly linked to relevant services such as health and education and to the overall *process* of a multi-sectoral programme - rather than being perceived as independent (health-sector) products.

Indicators of structural and environmental change communication	• Evidence of the impact of advocacy work reflected in citations, references and responses in grey literature, publications of governments, NGOs, and civil society, as well as invitations to speak, present or broadcast. • Evidence of direct policy actions or changes. • Evidence of media and ICT deregulation and legislation. Multi-sectoral involvements identifiable at the national level for HIV prevention, AIDS care, and support.
Indicators of public information environment communication	• Expanded public and private dialogue and debate. • Identifiable increases in family discussion; discussion among friends; discussion in community gatherings; coverage and discussion in news media; problem-solving dialogue; focus and discussion in entertainment media; and debate and dialogue in the political process. • Increased accuracy of the information that people share in the dialogue/debate. • Evidence of increased media coverage of HIV and AIDS. • Evidence of increased government transparency and accountability resulting from political commitment to HIV and AIDS and civil society/media watchdogs.
Indicators of community participation and dialogue communication	• Increased recognition and knowledge of issues among target audience, increased accuracy of information. • Increased negotiation and life skills evident amongst young people and children. • Community's cultural activities (sports, folk media, festivals, celebrations, songs, etc) engage with HIV issues. • New community-based programmes and initiatives have been launched to address HIV prevention, AIDS care and support. • Religious organisations and spiritual leaders are involved in prevention, AIDS care and support programmes. • The people centrally affected by HIV and AIDS voice their perspective in the debate and dialogue. • Individuals or groups seek further information or take action as a result of HIV and AIDS communications intervention. • New coalitions and alliances have emerged among community organisations to address HIV issues. • Improved inclusion of those most affected by HIV and AIDS and their concerns in policy-making forums. • Increased leadership roles for people disadvantaged by HIV and AIDS. • Community members have collectively taken decisions or passed resolutions about tackling HIV and AIDS

Appendix 2 Sensitive use of language to describe HIV and AIDS

Box 15 A guide for talking about HIV and AIDS

DO
Use 'HIV' to refer to the virus which is transmitted

DO
Use 'AIDS' to describe the condition where a person becomes ill due to an underlying HIV infection

DON'T
Use 'HIV' and 'AIDS' interchangeably

DO
Say someone is 'HIV positive' if they have taken a test that informed them they have the virus

DON'T
Use the term 'HIV/AIDS' unless it is the title of an existing document or work programme

DON'T
Use terms such as 'AIDS victim', 'HIV sufferers' and 'AIDS orphans'

DO
Talk about 'tackling' AIDS rather than 'combating' or 'fighting' AIDS

DO
Use the term 'AIDS' if you are in doubt

A number of NGOs and people with HIV and AIDS who were consulted by DFID in the development of the 'Taking Action' strategy raised concerns about the widespread use of the terminology 'HIV/AIDS'. Their concerns aren't based on political correctness but raise genuine concerns that the term 'HIV/AIDS' implies that HIV is the same as AIDS or that HIV is inevitably a 'death sentence'. In line with UNAIDS, DFID and other UK Government departments have decided to stop using the term 'HIV/AIDS', unless it is a technical title. We would be very grateful for your co-operation and support in carrying this forward.

The term **HIV** (Human Immunodeficiency Virus) is used to refer to the virus that is transmitted and **AIDS** (Acquired Immune Deficiency Syndrome) to describe the condition where a person becomes ill because of underlying HIV infection. For example, it would be correct to refer to someone being 'HIV-positive' if they had taken a test that informed them that they have the virus.

It is worth noting that someone is HIV-positive only if they have taken the test and so it is best, instead, to use the term 'people with HIV'. Estimates of HIV prevalence use data from sources such as antenatal clinics and national or household surveys where tests are performed on the blood of people with HIV who may or may not know they are HIV-positive. In publicising the findings, UNAIDS describes the results as the number of 'people living with HIV'. It is also proper to describe 'HIV infection' or 'HIV transmission' and to refer to programmes for 'HIV prevention'. But where a topic or subject is described e.g. 'national AIDS strategy' the term 'AIDS' is sufficient; it is inclusive of the full social and political concept as well as the medical conditions. In general it is best to refer to the 'AIDS vaccine' – this is because some candidate vaccines work by blocking HIV transmission, and others seek to prevent HIV from progressing to AIDS. 'AIDS' includes both.

HIV/AIDS can be used where it is the title of an existing document or work programme. Otherwise please avoid using the term as it causes confusion, as well as some offence. Within internal UK Government documents we should avoid the term unless it is contained in a title. If in doubt the term 'AIDS' will usually be best. Finally, some organisations and people with HIV and AIDS have raised concerns about the inadvertent use of 'victimising language', and so phrases such as 'AIDS victims' or 'HIV sufferers' are best avoided. Communications and behaviour change specialists also advise against the use of militaristic language, e.g. 'fighting AIDS', the 'war against AIDS', the 'battleground' as this has been shown to be unhelpful. Terms such as 'tackle', or perhaps 'struggle' are usually preferred.

Appendix 3

Key on-line resources on AIDS communications

AEGIS (www.aegis.org/)	Is the largest AIDS web site in the world. It contains a large, searchable database of news stories, newsletter articles, community materials and AIDS abstracts from journals and conferences.
AVERT (www.avert.org/)	Is a UK-based AIDS education and medical research charity that focuses on information about education to prevent infection with HIV, information for HIV-positive people and the latest news and statistics.
Centres for Disease Control and Prevention (www.cdcnpin.org /scripts/index.asp)	Is a broad US-based health and communicable disease site that features an HIV theme that addresses policy, planning and prevention issues. See: ● **Campaigns and initiatives** (www.cdcnpin.org/scripts/campaign/index.asp) ● **Satellite broadcasts** (www.legacy.cdcnpin.org/broadcast/start.htm)
Communications Initiative (www.comminit.com/)	Contains an impressive collection of user-friendly, regularly updated information on communications, with particular reference to communications and HIV and AIDS. See: ● **Proceedings of the VIII Communications for Development Roundtable (Managua, Nicaragua, 26-28 November 2001)** (www.comminit.com/roundtable2/background.html) ● **Communication Initiative's HIV and AIDS window** (www.comminit.com/hivaids/)
Johns Hopkins Centre for Communication Programs (www.jhuccp.org/)	Is a site produced by the Centre for Communication Programs with material on mass, participatory media interventions, as well as themed sections on specific communication responses to specific diseases. See: ● **HIV and AIDS at Johns Hopkins** (www.jhuccp.org/topics/hivaids.shtml)
OneWorld Radio AIDS Network (www. aidsradio.oneworld.net/index.php?)	Offers services and networking for broadcasters and civil society organisations who are interested in using radio/audio to promote awareness, news and public education on HIV and AIDS.
PANOS (www.panos.org.uk/)	Have addressed a broad range of issues related to HIV and AIDS including stigma and discrimination, men (including men who have sex with men), access to treatment, communication for development, support for regional activities produced. See: ● **HIV Communication** (www.comminit.com/pdf/panos_HIV_policy_paper_Nov_2002.pdf) ● **Communications for Development** (www.panos.org.uk/global/program_news.asp?ID=1002) ● **AIDS communication pages** (www.panos.org.uk/global/projectdetails.asp?ProjectID=1013&ID=1001)

Rockefeller Foundation Communication for Social Change (www.rockfound.org)	Is a site featuring useful publications relating to the foundation's work in communications for social change and development. See: ● **Communication for Social Change: A Position Paper and Conference Report, 1999** (www.rockfound.org/Documents/183/positionpaper.doc) ● **Communication for Social Change: An Integrated Model for Measuring the Process and Its Outcomes** (www.rockfound.org/Documents/537/table_contents.html) ● **'Making Waves' – stories of participatory communication for social change from the Rockefeller Foundation** (www.rockfound.org/Documents/421/makingwaves.pdf) ● **Talking Cure: A case study in communication for social change** (www.rockfound.org/Documents/615/decatur7_31.doc)
Soul City (www.soulcity.org.za/)	Is site tracing the history and activities of the Soul City multi-media health education vehicle used extensively in Southern Africa to address a range of health and community issues from AIDS to domestic violence.
UNAIDS (www.unaids.org/)	Is the joint UN programme on HIV and AIDS and features numerous publications on every aspect of HIV and AIDS, from social dimensions to specific publications on formal education, peer education and mass media. See: ● **Communications Programming** (www.unaids.org/en/in+focus/topic+areas/communications+programming.asp) ● **Community Mobilisation** (www.unaids.org/en/in+focus/topic+areas/community+mobilization.asp)
UNICEF (www.unicef.org/)	The United Nations Children's Fund tracks global issues facing children, including the effects of AIDS on young children. See: ● **UNICEF'S HIV and AIDS pages** (www.unicef.org/aids/index.html) ● **Strategies for Hope** (www.stratshope.org/) ● **Stepping Stones** (www.steppingstonesfeedback.org)
WHO (www.who.int/)	WHO (www.who.int/) is a site that addresses all major diseases and which provides a host of technical information and support material on HIV and AIDS. See: ● **HIV and AIDS pages** (www.who.int/topics/hiv_infections/en/)

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