TYPOLOGY OF COMMUNITY RESPONSES TO HIV AND AIDS

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Evaluation of the Community Response to HIV and AIDS
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Typology of the Community Response to HIV and AIDS

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Abstract:

In recent years there has been a significant increase in funding for civil society, including community organizations, to deliver HIV prevention, treatment and care and to mitigate the effects of the epidemic. However, there is limited evidence, based on robust evaluation, about which community responses are most effective, efficient and sustainable or how such responses can best complement the actions of governments and other actors. To address this, the World Bank and DFID are conducting an evaluation of community responses to HIV and AIDS.

As part of this evaluation, a background paper, based on a review of the literature, was commissioned to consider the following questions: What is meant by community response? What actors are involved in community responses? What activities are covered by community responses? Who are the main actors driving community responses?

The paper identifies criteria that could be used to define community responses to HIV and AIDS – the types of organizations and structures implementing the response; the types of activities or services implemented and the beneficiaries of these; the actors involved in and driving community responses; the contextual factors that influence community responses; the extent of community involvement in the response; and the extent to which community responses involve wider partnerships and collaboration. It then proposes a framework, with a set of questions corresponding to these criteria, that could be used to inform the evaluation and, specifically, to systematically map community responses to HIV and AIDS, to inform analysis of community responses and to support further analysis of the characteristics of effective community responses and of factors that influence community responses and scope for scale up.

Keywords:

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Table of Contents

Acronyms 6
Acknowledgments 7
Introduction 8
Defining community responses to HIV and AIDS 9
  Organizations and structures 9
  Activities and beneficiaries 11
  Actors 13
  Contextual factors 16
  Community involvement 17
  Partnerships and collaboration 18
Conclusion 20
Annex 1: Framework for analysis of community responses to HIV and AIDS 22
Annex 2: Bibliography and sources of information 24

DRAFT

Acronyms

ART	Anti retroviral therapy
ASO	AIDS service organisation
CBO	Community-based organisation
CSO	Civil society organisation
CSS	Community systems strengthening
DFID	Department for International Development (UK)
FBO	Faith-based organisation
IDU	Injecting drug user
MAP	Multi-country AIDS Programme
MSM	Men who have sex with men
NACO	National AIDS Control Organization (India)
NGO	Non-government organisation
OED	Operations Evaluation Department
OVC	Orphans and vulnerable children
PEPFAR	President's Emergency Plan for AIDS Relief (US)
PLHIV	Person or people living with HIV
PMTCT	Prevention of mother to child transmission
TASO	The AIDS Support Organisation (Uganda)
TB	Tuberculosis
UN	United Nations
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNDP	United Nations Development Programme
VCT	Voluntary counselling and testing
WHO	World Health Organization

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This report is the result of a consultative process carried out with the UK NGO Consortium for AIDS and Development and other key development partners, including DFID that was launched as part of a comprehensive evaluation of the community response in 2009. It is part of a series of background papers and publications aimed at clarifying key "building blocks" that underlie the evaluation of the community response to HIV and AIDS. These include:

1. Community response to HIV and AIDS: thematic areas for community evaluations
2. Typology of community responses to HIV and AIDS
3. Mapping of funding mechanisms for the community response to HIV and AIDS

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Introduction

Over the past two decades, development donors have paid increasing attention to the work done by community organizations in response to HIV and AIDS. Among others, civil society organizations (CSOs) have played an important role in offering innovative approaches to prevention, care, treatment, and support. Despite the fact that CSOs have made tremendous efforts to prevent HIV and mitigate its impact, the extent to which these organizations have been able to stem the epidemic has not been assessed or documented in a systematic and rigorous way. To date, support for these initiatives has largely been based on conventional wisdom and anecdotal observations rather than solid data.

In recent years there has been a significant increase in donor funding for civil society, including community organizations, to deliver HIV prevention, treatment and care services and to mitigate the effects of the epidemic. However, there is limited evidence, based on robust evaluation, about which community responses are most effective, efficient and sustainable or how such responses can best complement the actions of governments and other actors. An evaluation of the World Bank's HIV/AIDS assistance by the Independent Evaluation Group (IEG) of the World Bank in 2005 highlighted the need for better understanding of community responses including how these are organized and developed, their strengths and weaknesses, the types of activities and services undertaken and the effectiveness and quality of these activities and services.

To address these gaps, the World Bank's Global HIV/AIDS Program (GHAP)—in collaboration with DFID, the UK NGO AIDS Consortium, and other partners—launched an evaluation (in March 2009) to assess community responses to HIV and AIDS. Over its' two-year life span, the primary objective of this effort is to build a robust pool of evidence on the impact and cost-effectiveness of community-based activities and programs in up to ten countries in various regions, but with a strong concentration in the sub-Saharan African region.

As part of this evaluation, a review of the literature was undertaken to assess and analyze community responses to HIV and AIDS. The review, summarised in this background paper, aimed to address the following questions: What is meant by community response? What actors are involved in community responses? What activities are covered by community responses? Who are the main actors driving community responses?

The paper reviews ways in which the modalities of community responses to HIV and AIDS can be characterised or defined and proposes a framework for classifying the types of community responses and analyzing them.

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Defining community responses to HIV and AIDS

Before considering what is meant by the term 'community response', it is helpful to define what is meant by 'community' (see Box 1). A range of definitions is used but these broadly fall into two categories:

- Community as a form of identity or belonging – i.e. a group sharing common characteristics, circumstances and experiences, interests and concerns or behaviours. Communities can form when people work together or find that they share common needs and challenges, for example, people living with HIV (PLHIV), men who have sex with men (MSM) or sex workers.

- Community as a sense of place – i.e. a group linked by virtue of living in the same place, for example, a specific geographical location or administrative entity such as a village or town.

Box 1: Definitions of community

A UNAIDS review (1999) defines community as a specific group of people living in a common geographical area who share a common culture, are arranged in a social structure and exhibit some awareness of their identity as a group.
A UN review (2003) defines a community as 'a group of people who have something in common and will act together in their common interest'.

Review of the literature suggests that the modalities of community responses to HIV can be characterized or defined according to the following broad criteria, which are discussed in more detail below:

- The types of organizations and structures implementing the response.
- The types of activities or services implemented and the beneficiaries of these
- The actors involved in and driving community responses.
- The contextual factors that influence community responses.
- The extent of community involvement in the response.
- The extent to which community responses involve wider partnerships and collaboration.

Organizations and structures

The modalities of community responses to HIV and AIDS can be characterized or defined according to the types of organizations or structures involved. Box 2 provides examples of how organizations and structures have been categorised in different settings.

Box 2: Examples of how organizations and structures involved in community responses have been categorised

The DFID-funded Strengthening the HIV/AIDS Response in Zambia program, which has supported civil society participation in the national response, categorizes organizations as: grassroots and community organizations; national and international NGOs, FBOs and other more formalized civil society structures; civil society networks, umbrella bodies and associations; civil society platforms and forums. Around 75% of civil society organizations fall into the first two categories; over 22% have a religious affiliation.

Analysis of the National HIV/AIDS Database in South Africa (Birdsall, 2005) found that 162 of the 1,582 entries identified themselves as FBOs, which were categorised as: networks or coalitions (associations of churches or FBOs that facilitate coordination and communication among members); national or provincial structures (for example, dioceses); social services agencies (welfare and charitable wings); faith-based NGOs (NGOs with a religious orientation); congregations; and projects (for example, initiatives such as children's homes).

Figure 1 suggests an approach to categorizing the diverse types of organizations and structures that are involved in community responses. As shown in the figure, a distinction is often made between:

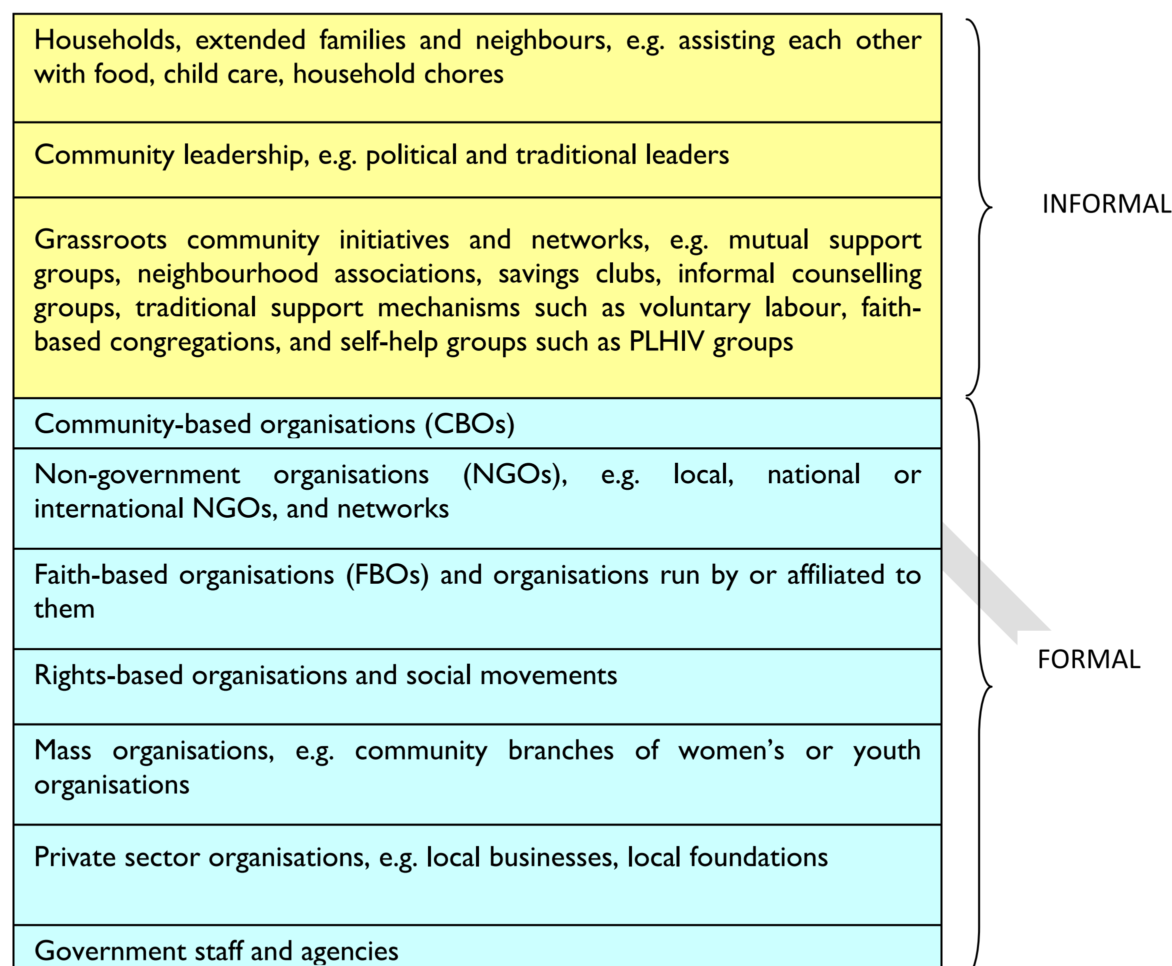
- 'Informal' grassroots or indigenous community initiatives and self-help groups.
- 'Formal' organizations such as community-based organizations (CBOs), non-government organizations (NGOs) and faith-based organizations (FBOs).

The former usually have no formal structure, rely on volunteers and operate without external support. The latter have some form of formal status with, for example, legal registration, a bank account, management committee, defined responsibilities and paid staff, and may receive external support.

Both informal and formal organizations and structures fall under the overall umbrella of civil society. For example:

- DFID (2006) states that 'civil society broadly means the groups and organizations which occupy a position between the household, the state and the private sector', and includes 'NGOs as well as think tanks, trades unions, faith groups, social movements, cooperatives, professional associations, and community groups'.
- UNAIDS defines civil society organizations (CSOs) as including AIDS service organizations (ASOs), PLHIV groups, youth and women's organizations, business, trade unions, professional and scientific organizations, sports organizations, international development NGOs and religious or faith-based organizations.

Figure 1: Formal and informal institutional arrangements



Most available information about community responses is based on case studies of activities implemented by formal organizations. Much activity by informal actors is not captured or documented. This is partly due to the fact that informal responses are often 'unstructured' and difficult to measure, such as grandparents caring for grandchildren. UNAIDS has noted that very few initiatives undertaken by rural households and communities to respond to the epidemic have been evaluated for their effectiveness and virtually none for their costs to society. Others have noted that community responses are under-researched compared with international and national level interventions and that, while there is a growing body of evidence, there have been few systematic studies.

Activities and beneficiaries

In the literature, the modalities of community responses are most often characterized or defined according to type of activities or services. For example, UNAIDS (1999) categorises responses into three broad areas – support and mitigation, treatment and care, and culture and norms – while others have mostly classified responses in relation to activities that fall under the three main areas of AIDS responses – prevention, treatment and care, and mitigation – or a variation on these.

Analysis of community responses shows that these involve a diverse **range of activities** and services, which can be categorized as follows:

- *Prevention* – for example, education, information and awareness raising, life skills, behaviour change, action to change harmful traditional practices, cultural or gender norms and to reduce stigma and discrimination, distribution of condoms, needles and bleach, HIV testing and related counselling, activities targeting groups at elevated risk or promoting uptake of HIV testing or prevention of mother-to-child transmission (PMTCT) services.

- *Treatment* – for example, medical care, treatment of opportunistic infections, referral to health facilities, treatment education and literacy, HIV and TB treatment adherence.

- *Care and support* – for example, social, psychological and spiritual support, counselling, child care, day and respite care, home-based care, palliative care, nutrition support, orphan and vulnerable children (OVC) support, support group and self-help activities.

- *Impact mitigation* – for example, savings and credit, vocational training, income generation, material and welfare support, agricultural support, food assistance, nutrition gardens, legal support and referral, welfare support and referral.

- *Advocacy and networking* – for example, community mobilisation to demand services, lobbying, policy dialogue, and rights activities.

Another way of categorising community responses is according to the intended target audience or **beneficiaries of activities** and services. While some activities and services address a geographic community as a whole, others target specific groups, for example:

- People living with HIV.
- People affected by HIV, for example, partners and families of PLHIV, widows, orphans and other vulnerable children.
- People at elevated risk of HIV, such as sex workers, MSM, injecting drug users, street children, migrant and mobile populations or specific population groups within the community such as women or youth.

The type of activities or services and the target group or beneficiaries appear to influence the extent to which community responses play a leading or a supporting role. For example, community responses tend to play a leading role where face-to-face interaction, knowledge of the community and peer influence and support are important, such as in care and support or in reaching populations that are at elevated risk of HIV. Community responses tend to play a supporting or complementary role where involvement of government or other agencies in providing services is important, for example, in treatment (see Box 3).

Box 3: The role of community responses

A study in South Africa (M'Zamani et al, 2007) found that 90% of community organizations were involved in prevention and 70% in care and support; involvement with treatment was more limited, with a focus on treatment literacy. The emphasis of non-state actors was on general rather than technical services. Community organizations were more active in care and support – more than 70% work with OVC – while government institutions were more active in delivery of services such as VCT and PMTCT.

The Commission on AIDS in Asia noted that community participation is critical to successful HIV prevention for people engaged in risk behaviours – studies show that more than 80% of drug users could be reached within 6 months with condoms and cleaning kits through peer outreach workers whereas interventions relying on local leaders, social workers and medical staff only reached 25%. It also highlighted the importance of community involvement in influencing norms, for example, sex worker-led safe sex efforts such as in the 100% condom use program in Thailand and the Sonagachi project in India.

Actors

The modalities of community responses can also be defined in terms of the actors that initiate or drive responses. Actors can be categorized as including:

- Individuals within communities.
- Community structures and organisations.
- Local and national NGOs and FBOs.
- International NGOs and FBOs.
- Multilateral, bilateral and UN agencies.
- National and local governments.

A UNAIDS review (1999) noted that some community responses are initiated from within communities, describing these as 'indigenous or grassroots responses', while others are introduced and financially supported by outside actors such as government, churches, NGOs or international agencies. Wilkinson-Maposa and Fowler (2009) use a similar approach, differentiating between vertical philanthropy (aided change) and horizontal philanthropy (self help and mutual assistance). Broadly speaking, community responses can be categorized as those:

- Initiated and led by the community.
- Initiated by the community but subsequently driven by non-community based actors.
- Initiated by external actors but subsequently led by the community.
- Initiated and led by non-community based actors.

Review of the literature also suggests that community responses are initiated by individuals or existing structures either in response to the needs of others in the community or in response to their own needs.

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With respect to the former, Foster (2002) describes small-scale, informal actions by groups of individuals motivated to care for those in need such as PLHIV and OVC, and UNAIDS describes community initiatives in Swaziland that involve volunteers in providing psychosocial support, counseling and home-based care to those affected by HIV. With respect to the latter, a review of PLHIV organizations in Mozambique describes 'groups directly affected organizing themselves' as a way of dealing with common problems, sharing difficulties, giving each other practical assistance and emotional support'. Similarly, community-driven responses cited in the Commission on AIDS in Asia report include MSM-initiated peer education and condom distribution for MSM in the Philippines and HIV information and support telephone hotlines for MSM in China. In Brazil, sex workers, transvestites, MSM and street children have established their own CSOs to carry out support and prevention activities. These groups often have a better understanding of the target population and of what methods may or may not work to modify high risk behaviors, and being closer to the ground allows them to interact with sometimes transient populations that may be suspicious of government.

There are some examples of community responses initiated by non-community based actors and led by communities, for example, the Sonagachi Project in India, which supported sex worker-led efforts to prevent HIV. However, most documented examples are of responses initiated by communities and subsequently supported by non-community based actors (see Box 4).

Box 4: Examples of non-community based support for community-initiated responses

In Malawi, Word Alive Ministries International, a church-based community organization started providing HIV counseling in 1992 and home-based care in 1996. Services have since expanded with funding from USAID and CIDA. In Zimbabwe, Island Hospice and Bereavement Service, set up to provide care and support for people with cancer, also subsequently expanded its services to include care and support for PLHIV with donor funding.

The Alliance uses a Linking Organization approach, where larger national NGOs support community organizations. Examples include: PHANSuP in the Philippines, which has supported Pinoy Plus, a self-help group for PLHIV, to carry out peer counseling and advocacy, and IWAG to mobilize action among gay men; COMUNIDEC in Ecuador, which has supported FAES, a transvestite group, to implement HIV prevention activities; and IPC in Burkina Faso, which is supporting local organizations to integrate HIV work, small scale loans and health insurance schemes, to enable affected households to care for OVC and pay for medical costs.

The Tides Foundation, ICW and Women and Children's Collaborative Fund for Treatment Literacy in Africa provide small grants to grassroots organizations working with women and children in advocacy, HIV treatment literacy and economic autonomy.

CARE supports community-driven responses in Rwanda, for example, the Strengthening Communities Response to HIV/AIDS Project used savings and loans groups as an entry point for community-driven HIV prevention, care and support and provided training and support for CBOs and PLHIV associations.

The intervention or assistance of external organizations has played a key role in developing informal initiatives into formal community organizations – formalizing systems is usually a prerequisite to accessing external funding – and in expanding the scope or geographical coverage of activities. Russel and Schneider (2000) cite examples of organizations that grew out of community initiatives including The AIDS Support Organization (TASO) in Uganda and the Family AIDS Caring Trust (FACT) in Zimbabwe.

Among non-community based actors, **donor agencies** have been especially influential in catalyzing and building on community responses. Increased donor funding, in particular from the World Bank, the Global Fund and PEPFAR, has played a critical role in driving, and setting the agenda for, community responses.

- The World Bank MAP channelled 38% of its funding to CSOs, including support for community responses to HIV and AIDS, between 1999 and 2005.
- The Global Fund recommends that proposals include community systems strengthening activities, defined as 'financial, technical and other support to organizations and agencies that work directly with and in communities…'
- PEPFAR has provided a significant amount of funding for community responses, mostly through international NGOs. The PEPFAR New Partners Initiative is awarding grants totaling US$200 million to new partners to provide prevention and care services in the 15 PEPFAR focus countries. The focus is on FBOs and CBOs; partners include US, international and national NGOs that act as intermediaries with these community organizations.

M'Zamani et al (2007) note that 'It is clear that there is strong demand within communities for HIV/AIDS activities of many different sorts, as evidenced by the organic emergence of community initiatives – many of which began as purely volunteer efforts. It is also evident that there is funding available to support such activity'. However, they also note that 'What is more difficult to unravel is the interplay of these elements of demand … and supply … and the extent to which one or the other can be said to be a driving force'.

According to a review of the role of civil society organizations in Nigeria, accessing external money is a key factor driving community organizations' responses to HIV, in contrast with Uganda where the response was initially internally driven. In some contexts, NGOs and CBOs have been established in order to capture external funding and these organizations have little connection with the communities they claim to represent or serve.

Some authors have also questioned the extent to which external funding strengthens local ownership of responses, suggesting that this may be undermined by prescribing 'fundable activities' in accordance with priorities set outside the community. M'Zamani et al suggest that NGOs and CBOs may be motivated by survival, leading them to tailor their activities to available funding opportunities. Kelly and Birdsall highlight the potential adverse impact on the independence and sustainability of civil society of the drive to scale up HIV responses using community organizations as implementing agencies.

Other non-community based actors that have played a key role in community responses to HIV and AIDS include:

- UN agencies – for example, UNDP initiated Community Conversations, an approach that involves facilitated dialogue in the community.
- International NGOs – for example, the Naz Foundation International supports MSM networks and groups to establish HIV services.
- Governments – for example, in Lesotho, the Essential HIV and AIDS Services Package is a collaborative approach by the Ministry of Local Government and Chieftainship and National AIDS Commission, through which all Community Councils have made plans for implementing HIV interventions in their communities.

In addition to funding, non-community based actors provide a range of other support for community responses. This includes capacity building and organizational development, technical assistance, and support for networking and coordination (see Box 5). A UNAIDS best practice document (1999) also highlights the role of lessons from experience elsewhere and of international guidance in driving community responses. For example, Cambodia's home care programme, a collaboration involving community-focused NGOs and the Ministry of Health, drew on the experience of TASO in Uganda, NGOs in Thailand and WHO guidance.

Box 5: Range of external support, and support mechanisms, for community responses

A study in South Africa (Birdsall et al, 2007) documented seven models for funding and coordinating community responses: a private grant-making institution; CBO mentoring organization; membership network of groups working with affected children; small grants scheme; provincial health department collaborating with NGOs; umbrella network for ASOs; and a community clearinghouse for AIDS activity. All provide support to community organizations through funding, capacity building or networking in order to foster and promote community-level action. Two of these models – the Children in Distress Network and the AIDS Foundation – have their origins within the communities they serve; the other five were initiated by external actors including government departments.

Contextual factors

The country context influences the modalities of community responses. For example, differences between the way in which TASO in Uganda and the Treatment Action Campaign in South Africa developed and expanded are attributed to differences in the political context, the government response to HIV and to civil society and the priorities of the donor community, among other issues.

The **epidemic context** in particular drives community responses and the types of activities undertaken. In sub-Saharan Africa, much documented experience describes community responses in terms of PLHIV and OVC support, whereas in Asia examples tend to highlight responses driven by 'communities' most at risk of HIV infection such as sex workers and MSM.

Community responses have also evolved as the epidemic has evolved. For example, NGOs working on AIDS issues in Brazil focused initially on fighting social exclusion and pressuring the government to be more responsive – NGO leadership was instrumental in creating the legislation to mandate nationwide HIV testing of blood donations, and NGOs created home care programs, established HIV support groups and launched preventive efforts. In Zimbabwe, the Families, Orphans and Children Under Stress (FOCUS) programme has evolved from an initial focus on home-based care and awareness raising to encompass support for affected children.

As treatment has become more widely available, community organizations have increased their involvement in treatment-related activities or changed the emphasis of their work. For example, in South Africa, the Treatment Action Campaign has expanded its work on treatment access to include mobilizing community involvement in treatment education and treatment adherence.

Responses are also driven by **location**. For example, a mapping of community responses in three settings – a large urban township, a small town and a rural area – in South Africa (M'Zamani et al, 2007) found very few organizations operating in the rural area – the only examples of activities were outreach conducted by churches and home care provided by a local NGO. In contrast, there were 67 and 104 organizations respectively in the town and urban township, involved in a range of activities including support groups, home-based care, spiritual support, condom distribution and provision of transport to clinics for PLHIV.

Another review in South Africa (Birdsall, 2005) also found that services provided by FBOs depended on the setting. FBOs in rural areas were less involved in food programmes but more involved in condom distribution than FBOs in urban areas, and a higher proportion of FBOs in urban areas reported involvement in care and support. Most FBOS in rural and urban areas provided services to PLHIV, OVC and HIV-positive mothers, but in urban areas FBOS were more likely to also provide services to substance abusers, sex workers and street children.

Community involvement

The modalities of community responses can also be categorized according the extent of community involvement. This is often closely related to whether or not the response is initiated and led by the community or by external actors.

Community involvement can be described along a continuum that ranges from collective responses driven and led by communities to 'co-option' of communities – with various degrees of community consultation, community participation and community mobilization in between.

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For example, a study of PLHIV involvement in community-based programs (International HIV/AIDS Alliance and Horizons, 2002) identified a spectrum of five 'areas of involvement': use of services; support to services; delivery of services; planning and design of services; and management, policy making and strategic planning. PACT Cambodia involved the national Cambodian PLHIV network CPN+ and its eight provincial networks in implementing a one-year programme called the Community Response to Reducing HIV/AIDS Stigma and Discrimination. PLHIV were involved in programme design and implementation, empowered to advocate for their rights and to gain the support of their communities through community forums, and strengthened the capacity of PLHIV organizations.

Informal responses, which are initiated and led by communities, are an important manifestation of community involvement but, as discussed above, are not well documented. Most examples in the literature involve a non-community-based agent mobilizing or facilitating the mobilization of communities. In such externally-driven responses a key factor influencing the degree of community involvement is the extent to which non-community-based actors work through and strengthen existing community structures rather than displacing or duplicating them.

Community responses, and the extent of community involvement, may also be influenced by the characteristics of communities, such as capacity, skills and social capital i.e. shared norms and social networks, which enable community members to engage in common action.

Partnerships and collaboration

The modalities of community responses can also be categorized according to the extent to which these involve different actors working together within and across sectors, and the different ways in which partnerships and collaboration are structured and managed (see Boxes 6 and 7).

Box 6: Partnerships and collaboration in South Africa

A community audit in South Africa (Birdsall and Kelly, 2005) found that 88% of CBOs and NGOs and 50% of FBOs network with other organizations, but few had formal partnerships. The Departments of Health and Social Development use CBOs and NGOs as service delivery partners; service-level agreements are one of the clearest examples of partnerships. Another interface between community organizations and government is local planning and coordination of the AIDS response, although formal coordination is limited in the communities surveyed.

Review of the literature indicates that these modalities include:

- *Umbrella groups, networks and coalitions* – these involve alliances between groups with common interests or activities, often driven by key individuals within community organizations and NGOs or by external actors such as international NGOs, FBOs or donors. Coalitions tend to focus on advocacy while networks tend to focus on

information sharing, coordination and support to member organizations, although the distinction is not always clear cut.

- *Formal partnerships* – these include formal agreements between community organizations and government or other organizations for delivery of specific services. Formal service delivery agreements are mostly initiated by external actors including government agencies, international NGOs and donors.

- *Referral relationships* – community organizations may have links with services without any formal partnership agreement, for example, with facilities that provide HIV counseling and testing or with education or social welfare services. Such links are initiated both by community organizations and by external actors.

- *Coordination mechanisms* – these include local AIDS councils or forums. Coordination mechanisms are usually established by government although there are examples of mechanisms initiated by NGO umbrella groups, coalitions and networks.

- *Informal collaboration* – many community organisations have informal links with other organisations on an *ad hoc* basis.

Box 7: Partnerships and collaboration in Brazil

The AIDS/STD Control Project in Brazil demonstrated that government-NGO partnerships can work well. NGOs provided the link to people at local level and helped the government to reach vulnerable populations such as MSM, drug users, sex workers and street children. A successor project is continuing to foster collaboration between government officials, NGO practitioners and donors. In addition, over time, CSOs have established national and regional networks, in order to exchange information and more effectively influence public policy.

Partnerships and collaboration can be internally or externally driven (see Box 8). There is little in the literature concerning factors that enhance or limit partnerships, although Birdsall and Kelly (2005) identified competition between community organizations for funding, clients and territory and external support for new organizations as factors that work against partnerships and collaboration. Enhancing factors include a critical mass of organizational activity in an area, local government officials supportive of community activism on HIV, and the presence of a training or capacity building organization.

Box 8: Examples of joint working

Examples of 'internally driven' joint working include:

- In South Africa, the Children's HIV/AIDS Network ensures coordination between over 400 partners including NGOs, CBOs, communities, home-based carers, children's homes, day care centers, FBOs, businesses, unions, academic institutions, health facilities and government departments, e.g. health, education, social services and poverty alleviation.
- The Kenya AIDS NGO Consortium, a national membership network of over 1,000 NGOs, CBOs and FBOs working in HIV, was established to enhance networking and collective action.

Examples of 'externally driven' joint working include:

- In Nigeria, the Civil Society Consultative Group on HIV/AIDS, a national forum with over 350 members, was facilitated by Action Aid and Family Health International with DFID funding.
- In Côte D'Ivoire an out-patient clinic for PLHIV initiated by an international FBO, Hope International, is linked to the Ministry of Health and University Hospital.
- In India, a continuum of care project, initiated by the state government, NACO, WHO, Oxfam and local NGOs, included multidisciplinary core groups in hospitals, NGOs and communities.
- In Brazil, the World Bank encouraged NGO participation in the AIDS/STD Control Project, as NGOs can complement government action with their flexible, innovative, and cost-effective approach, can reach and work effectively with people at the community level, especially the most vulnerable, and NGO involvement is in keeping with the Bank's participation policies.

Conclusion

Community responses to HIV and AIDS are diverse, and often country and context specific.

- Community responses to HIV and AIDS involve a wide range of actors, encompassing informal and formal organizations and structures. This diversity represents a challenge for evaluation of community responses. Available evidence about community responses is largely based on case studies of activities implemented by formal organizations, and the activities of informal actors are not systematically captured or documented.

- Community responses may be initiated by individuals or structures within the community to respond to the needs of others in the community, for example, PLHIV or OVC, or in response to their own needs, for example, MSM, or driven by external actors. External actors and funds have played a critical role in catalyzing and expanding community responses.

- Community responses involve a wide range of activities and services, including prevention, treatment, care and support, impact mitigation, advocacy and networking, to meet the needs of people living with or affected by HIV and people who may be at elevated risk of HIV. The nature of these activities and services depends on factors such as the country and epidemic context, the location of the community, the actors initiating or leading the community response and the intended target group or beneficiaries.

- Community responses appear to play a critical role in certain aspects of the HIV response in some contexts, for example, advocating for access to services and providing care and support for those most affected by the epidemic, and in peer efforts among marginalized populations. Community responses can also contribute to supporting services provided by government, for

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example, encouraging uptake of HIV testing, challenging stigma and discrimination, and supporting treatment adherence.

- Community responses demonstrate a range of community involvement and of modalities for partnerships and collaboration with other actors. Community responses that work in partnership or collaborate with other actors can help to link communities to a wider range of services.

The diversity of community responses makes it difficult to develop a single definition of the 'community response'. However, responses can be categorized according to the following criteria:

1. The types of organizations and structures implementing community responses.
2. The types of activities that are implemented and the beneficiaries of these.
3. The actors involved and driving community responses.
4. The contextual factors influencing community responses.
5. The extent of community involvement in the response.
6. The extent to which community responses involve partnerships and collaboration.

Corresponding to each of these criteria, a set of questions could be asked in order to obtain a description of community responses, which can be used to inform the evaluation of community responses to HIV and AIDS (the criteria and related questions are presented in a framework in Annex 1). Such a framework can be used:

- To systematically map community responses to HIV and AIDS in different settings. The strength of this approach is that it would allow informal community responses to be documented that might not be captured using other approaches.

- To inform analysis of community responses, for example, what types of actors deliver what types of services to which beneficiaries in a range of country contexts, at what costs and with what outcomes.

- To support further analysis, for example, of the characteristics of effective community responses (see Box 9) and of factors that influence community responses and scope for scale up, for example, community involvement, external support, partnerships and collaboration.

Box 9: Partnerships and collaboration in Brazil

An Operations Evaluation Department's (OED) study looked at the AIDS/STDs Control Project in Brazil as part of an effort to understand what difference NGOs make to the performance of World Bank-supported projects. The study hypothesized that NGO effectiveness is the product of: the existence of an enabling environment for their participation; a positive relationship between NGOs, governments and the World Bank; and NGOs' local knowledge, flexibility, and innovation.

Annex 1: Framework for analysis of community responses to HIV and AIDS

Broad criteria:	Specific questions:
Organizations and structures	• What are the main organizations or structures involved in the community response (e.g. community group, CBO, NGO, FBO, national NGO or FBO, international NGO or FBO, rights-based organization, mass organization, private sector organization)? • What is the type of community organization (e.g. informal grassroots or formal organization)? • What is the main focus of the organization (e.g. is the primary focus on HIV or HIV has been added to an existing portfolio of activities)? • What is the organization's institutional arrangements and capacity (e.g. mission, management structure, membership, governance, systems for planning, finance and M&E, implementation approach, paid staff and volunteers)? • What are the organization's budget, funding sources and funding channels (direct or through an intermediary)?
Activities and beneficiaries	• What are the main areas of activity (e.g. prevention, treatment, care and support, impact mitigation, advocacy, networking) and specific activities and services provided? • What is the scale and reach of activities? • Does the community response play a leading role or a supporting or enhancing role in different areas of activity? • Have activities evolved over time (e.g. in response to external actors, availability of funding)? • Has geographical coverage evolved over time (e.g. in response to external actors, availability of funding)? • Who are the target audience (e.g. the whole community or specific target groups)? • What is the perception of beneficiaries about the quality of services provided?
Actors driving the response	• Was the response initiated by actors within the community (e.g. individuals, existing community structures or groups) or external actors (e.g. local, national or international NGOs or FBOs, multilateral, bilateral or UN agencies, or government)? • Have the drivers changed (e.g. the response was initiated by communities but subsequently supported by external actors)? • Who leads the response (e.g. initiated and led by community, initiated and led by external actors or initiated by external actors and led by the community)? • Does the community response receive external support? • What is the source of external support (e.g. donor agency, UN agency, government, international NGO or FBO, national or local NGO, private sector)? • Has external support influenced the community response? • What type of external support is provided (e.g. funding, capacity building, technical assistance, support for networking and coordination) and how effective are different types of external support? • When did external support commence and what is the duration of external support?

Broad criteria:	**Specific questions:**
Contextual factors	• How has the political, social, economic context influenced the community response? • How has the epidemic context influenced the community response? • Have activities changed as the epidemic or the national response to it has evolved? • How has the location (e.g. urban, rural) influenced the community response?
Community involvement	• To what degree is the community involved (e.g. community leads, actively participates, supports, is informed, and is co-opted)? • What activities or interventions is the community involved in (e.g. identifying problems, needs and priorities, planning and design, implementation and service delivery, M&E)? • To what degree are target groups or intended beneficiaries involved? • What are the characteristics of the community (incentives, capacity, skills and social capital i.e. shared norms and values and social networks)?
Partnerships and collaboration	• Is the community response linked to other community organisations? • Is the community response linked to government structures, providers and agencies (e.g. local government, local AIDS committees, health facilities, social welfare services, and education or justice departments)? • Are referral systems in place between the community response and service providers? • What partnership modalities are in place (e.g. formal partnerships and MOU, informal partnerships and collaboration)? • Do actors in the community response participate in coordination mechanisms, networks, umbrella organisations or coalitions? • Which actors are driving partnerships and collaboration (e.g. internally or externally driven)?

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Annex 2: Bibliography and sources of information

The following websites and databases were searched:

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