

POLICY RESEARCH WORKING PAPER

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# Analyzing Community Responses to HIV and AIDS

## Operational Framework and Typology

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## Abstract

This paper presents a framework for analyzing the community response to HIV and AIDS. On the basis of a review of the literature, six criteria are proposed for characterizing such community responses: (1) the types of organizations and structures implementing the response, (2) the types of activities or services implemented and

the beneficiaries of these, (3) the actors involved in and driving community responses, (4) the contextual factors that influence community responses, (5) the extent of community involvement in the response, and (6) the extent to which community responses involve wider partnerships and collaboration.

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# ANALYZING COMMUNITY RESPONSES TO HIV AND AIDS: OPERATIONAL FRAMEWORK AND TYPOLOGY

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## Acronyms

ART	Anti-retroviral therapy
ASO	AIDS service organization
CBO	Community-based organization
CRS	Catholic Relief Services
CSO	Civil society organization
CSS	Community systems strengthening
DFID	Department for International Development (UK)
FBO	Faith-based organization
GFATM	Global Fund to fight AIDS, TB and Malaria
GHAP	Global HIV/AIDS Program
HCT	HIV Counseling and Testing
IEG	Independent Evaluation Group
IDU	Injecting drug user
MAP	Multi-country AIDS Programme
MSM	Men who have sex with men
NACO	National AIDS Control Organization (India)
NGO	Nongovernmental organization
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 Organization (Uganda)
TB	Tuberculosis
UN	United Nations
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UNDP	United Nations Development Programme
WHO	World Health Organization

# 1. Introduction

Historically, communities have been at the forefront of movements in support of their own needs. In the development sector, the World Bank has applauded and supported community-driven development for many years. The agriculture sector has relied on community groups to initiate new programs or changes in farming practices. Community-based activities have been the cornerstone of many health initiatives, such as vaccination and sanitation campaigns. The HIV movement has built on experiences such as these, and since the beginning of the HIV epidemic, civil society organizations have been in the vanguard of the community response to HIV and AIDS. Over the past two decades, development donors have paid increasing attention to the work done by CSOs. Among other things, these organizations have played important roles by offering innovative approaches to prevention, care, treatment, and support and by advocating for governmental responses. 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 been based largely on conventional wisdom, the assessments of CSOs themselves and their partners, anecdotal observations and context-specific case studies.<sup>2</sup>

Since 2000, there has been a significant increase in donor funding for civil society, including community organizations and initiatives,<sup>3</sup> to deliver HIV prevention, treatment, and care services and to develop associated advocacy activities that address the consequences of the epidemic. In total, recent estimates suggest that the four donors (most actively involved in the AIDS response (PEPFAR, GFTAM, World Bank and DFID) have provided almost \$500 million a year for civil society AIDS activities in recent years.<sup>4</sup> While large in absolute terms, these funds represent only 7.6 percent of the total international financial assistance provided by multilateral and bilateral donors.

The rationale for such support is that the community response is a key component of a national response. Some stakeholders go even further and assert that a national plan cannot be fully successful without a strong community component, as communities play a key role in halting

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<sup>2</sup> In addition to published materials, numerous internal project documents, reports, briefs, and opinions papers, as well as specialists, have been consulted in the preparation of this paper. These are not included in the list of references.

<sup>3</sup> In this paper we utilize “community-based initiative” as the generic term that is inclusive of civil society organizations (CBOs, NGOs, FBOs and the like) as well as informal community responses and entities that are not adequately classified as “organizations”.

<sup>4</sup> Funding Mechanism for the Community Response to HIV and AIDS. Draft Paper. AIDS Evaluation Team, World Bank, November 2010

new infections, supporting the sick and vulnerable, and mitigating the effects of the epidemic. The financial crisis of 2008, however, turned the upward funding trend into a plateau, and there are concerns that it may now go in reverse. At the same time, after years of increasing funding until 2008, there is now an acknowledged need to understand better which community responses are most effective, efficient, and sustainable and how such responses can best complement the actions of governments and other actors. Robust data are needed.

An evaluation of the World Bank's HIV/AIDS assistance efforts by the Bank's Independent Evaluation Group (formerly OED) in 2005 highlighted the need for a better understanding of community responses. Such an understanding would include how they are organized and developed, what their strengths and weaknesses are, what types of activities and services they undertake, and how effective and of what quality their activities and services are.

To address these questions, the World Bank's Global HIV/AIDS Program team, HNP -in collaboration with DFID, the UK Consortium on AIDS and International Development, and other partners -launched in 2009 an evaluation exercise that includes collecting primary data to assess the results achieved by community responses to HIV and AIDS. The primary objective of this effort is to build a more robust pool of evidence on the impact and added value of community-based activities and programs in a cluster of countries, with a strong concentration on the Sub-Saharan African Region.

As part of that effort, the present desk study was conducted to inform the approach of the overall evaluation. The paper describes ways in which the typology of community responses to HIV and AIDS can be characterized or defined and proposes a framework for classifying the types of community responses and analyzing them in a systematic way. The typology can also be applied to different themes and sectors, not only to HIV and AIDS. Thus, the paper provides a framework for analyzing complex communities and developing community typologies. It helps lay the groundwork for and describes the operational context of the larger evaluation that will address the issues of community response. This paper does not report empirical findings, as the actual field studies are currently ongoing.

## 2. Defining Community and Community Responses

*Communities* can be described in at least two different ways: culturally and geographically, or a combination of both. (See box 1.)

**Community as cultural identity:** Members belong to a group that shares common characteristics, circumstances, experiences, interests, concerns, or behaviors. Communities can form when people work together or find that they share common needs and challenges. A

community could be made of, among many others, people belonging to a religious community or church, people living with HIV (PLHIV), men who have sex with men (MSM), or sex workers.

**Community as a geographic sense of place:** It could be a group linked by virtue of living in the same place - a specific geographical location or administrative entity, such as a village or town.

Regardless of whether communities identify themselves in cultural or in geographic terms, they organize themselves in various ways to solve problems that affect the community and its members, and do so in order to bring about changes and improvements. One can hypothesize that supporting communities to reach their full potential would result in better development outcomes and long-lasting impacts. Figure 1 presents a linear logical framework that depicts hypothesized causal relationships in how community-based interventions may help achieve better development outcomes and impact.

There are multiplicities of combinations that fall under community response. It is worth noting that not all community responses are organized within local or national frameworks, but that there are also responses that are sub-regional in nature, thereby crossing national boundaries. This emphasis on sub-regional framework is warranted given the fact that HIV and AIDS have important transnational features (for example due to migration).

The UNAIDS (1999) review notes 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, religious networks, NGOs, or international agencies. More generally speaking, community responses can be categorized as being instigated by actors in the following ways:

- Initiated and led by the community with community resources
- Initiated by the community but subsequently driven by external actors and resources
- Initiated by external actors but subsequently led by the community with external or internal resources
- Initiated and led by external actors who provide goods and services directly in the community.



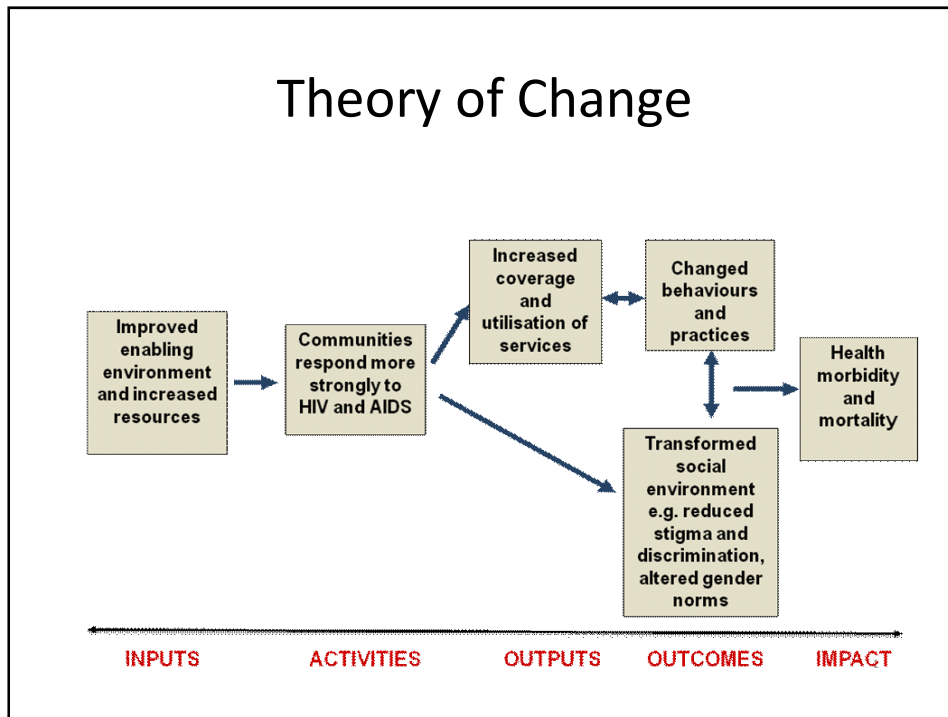
### Box 1: Definitions

Community refers to 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. UNAIDS (1999)

Community refers to a “a group of people who have something in common and will act together in their common interest.” UN (2003)

Community response refers to the combination of actions and steps taken by communities, including the provision of goods and services, to prevent and/or address a problem in order to bring about social change. Adapted from the Center for Community Change: [www.communitychange.org](http://www.communitychange.org)

Figure 1: From Inputs to Impacts: Logical Framework



Source: R. Rodriguez-García, 2009.

How community groups are created is not well understood. Sometimes several individuals create grassroots groups that remain informal and are more or less active based on need - for instance, to respond to a flood or a drought, to help rehabilitate a school, or to help with HIV and AIDS patient transportation. While these examples may appear to suggest that informal community-based groups are driven by the need to respond to short-term events, in fact many of the informal needs-driven responses that have been mapped have been in place for some time and are part of long-lasting informal mechanisms of solidarity. At other times, groups have organized themselves more formally, with a written mission, organized volunteers or staff, and

resources. Some groups incorporate themselves formally into organizations that go on to become members of national and international networks.

There is a high degree of diversity between, say, a group of students organized for community service, a group of grandparents helping orphans in their village, and a community-based organization that has become a legal entity with resources, skills, reach, and responsibilities. In the case of HIV and AIDS, field observation shows that community based organizations and initiatives are engaged in prevention, referrals, OVC-support, and home-based support and, increasingly, serve as interfaces between outreach activities, care and treatment; between the community and the public health system (UNAIDS 2005). They are especially valuable in reaching vulnerable populations and in advocacy. The definition of *community response* adapted for this paper would include all the varieties of community-based groups.

### **3. Dimensions and Typology of Community Responses**

Community responses can be characterized or defined according to many different criteria. In this section, we propose to consider six such criteria, and posit that these criteria are useful to analyze the response of a community to many different types of problem-context. This typology has emerged from consensus reached through a rigorous consultative process.<sup>5</sup>

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

#### **3.1. Organizations and structures**

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

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<sup>5</sup> For a list of persons and organizations consulted, see the Annex to the paper.

### **Box 2: Examples of how organizations and structures involved in community responses have been categorized**

The DFID-funded program Strengthening the HIV/AIDS Response in Zambia, which has supported civil society participation in the national response, categorizes organizations as (1) grassroots and community organizations; (2) national and international non-governmental organizations (NGOs), faith-based organizations (FBOs), and other more formalized civil society structures; (3) civil society networks, umbrella bodies, and associations; and (4) civil society platforms and forums. Around 75 percent of civil society organizations fall into the first two categories; over 22 percent have a religious affiliation (Collins, Simwanza and Mumbi 2009).

An analysis of the National HIV/AIDS Database in South Africa found that 162 of the 1,582 entries identified themselves as FBOs, which were categorised as (1) networks or coalitions (associations of churches or FBOs that facilitate coordination and communication among members); (2) national or provincial structures (for example, dioceses); (3) social services agencies (welfare and charitable wings); (4) faith-based NGOs (NGOs with a religious orientation); (5) congregations; and (6) projects (initiatives such as children's homes) (Birdsall 2005).

A large number of different typologies and nomenclature have been used in the literature to describe *types* of civil society organizations and initiatives. The *type* of entity often informs the basis for research and evaluation processes – and has resulted in a varied body of information that makes cross-analysis and comparison difficult. Differing classifications of type thus remains a challenge to any systematic analysis of community response which seeks to be inclusive of both formal organizational response (such as that by non-governmental organizations who are named in national databases), as well as informal community *initiatives* which might not have any organizational (or physical) structure and be significantly more fluid in nature.

A first useful distinction can therefore be made between *informal* and informal community initiatives, as described in box 3.

### **Box 3: Distinguishing between formal and informal community-based initiatives**

***Informal community initiatives:*** usually have no organizational infrastructure, might not have an actual facility, often rely on voluntary effort, and operate without external support. However, they may have social support structures and systems. For example, grassroots or indigenous community initiatives and self-help groups.

***Formal community initiatives:*** usually have some form of institutional infrastructure and status that might include a facility, legal registration, a bank account, a management committee, defined responsibilities, paid staff, strategic plans, and they may receive external support. Others may have all the characteristics of institutional status but may be denied legal registration because of the stigma attached to their work and/or the people they represent. For example, community-based organizations (CBOs), non-governmental organizations (NGOs), faith-based organizations (FBOs).

Efforts continue towards establishing more effective classification systems – for example, to more effectively differentiate sub-categories for faith-based initiatives – however, no single typology has been generally adopted (see Olivier 2011, UNAIDS 2009c).

As mentioned earlier, in seeking a comprehensive and systematic understanding of community responses, it is necessary to be inclusive of a wide range of *types* of community initiatives – many of which do not fit easily into current classification systems. Figure 2 suggests an aggregated approach to incorporating and categorizing the diverse types of organizations and structures that are involved in community responses:

**Figure 2: Formal and informal institutional arrangements for community-based initiatives**

	Most informal	Households, extended families, and neighbours assisting each other with, e.g., food, child care, household chores, or home-based care
		Community leadership, e.g. political, religious and traditional leaders
		Community initiatives, e.g., mutual care and support groups, neighborhood associations, savings clubs, informal counselling groups, and traditional support mechanisms such as voluntary labour, some faith-based congregations, and self-help groups such as PLHIV groups
		Community-based organizations, e.g. faith-based programs, community associations
		Nongovernmental organizations and networks (working at local, national, and international levels), e.g., faith-based non-governmental organizations, intermediaries, national health networks, multisectoral collaborative platforms, district level HIV/AIDS task forces, interfaith HIV and AIDS councils, local leadership councils.
		Rights-based organizations and social movements
		Mass organizations, e.g., community branches of women’s or youth organizations, faith-based movements, national networks of PLHIV
		Private sector organizations, e.g., local businesses, local foundations
	Most formal	Government staff and agencies

Source: Authors.

Both informal and formal community-based organizations and initiatives can fall under the overall umbrella of civil society.

- “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 union, faith groups, social movements, cooperatives, professional associations, and community groups.” DFID (2006)

- Civil society organization definition includes AIDS service organizations (ASOs), PLHIV groups, youth and women’s organizations, business organizations, trade unions, professional and scientific organizations, sports organizations, international development NGOs, and religious or faith-based organizations. UNAIDS (2008)

### ***3.2. Activities and beneficiaries***

Most available information about community responses is based on context-specific case studies and assessments of activities implemented by formal organizations. Much activity by informal actors is not systematically captured or documented. This is due partly to the fact that informal responses are often unstructured and difficult to measure, such as grandparents caring for grandchildren. It could also be due to the extreme variability of community response in different contexts. Few initiatives undertaken by rural households and communities to respond to the HIV epidemic for example have been evaluated for their effectiveness and virtually none for their costs or contributions to society.

Community responses are most often characterized or defined according to the types of activities or services they provide and the people they reach. UNAIDS (1999) categorizes responses in three broad areas: support and mitigation, treatment and care, and culture and norms. Other classifications are made in relation to a spectrum of activities -service delivery, community mobilization, governance, and financing -or a variation of these.

***Activities and services.*** An analysis of community responses shows that they involve a diverse range of activities and services. These are often characterized by the community’s ability to reach individuals beyond the reach of government and other institutions (GFATM 2010). The type of actions and activities that communities engage in can be clustered by purpose into two main categories: (1) those related to ensuring utilization of prevention and other services, care and support and impact mitigation whether provided by the community or by the public or private sectors; and (2) those related to creating an enabling environment for policy and advocacy, to fostering dialogue with leaders, to reducing stigma and discrimination, and to raising funds. (See box 4.)

#### **Box 4: Added-value of community activities in Brazil**

A World Bank Independent Evaluation Group 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 (Boyd and Garrison 1999).

More specifically, communities are typically involved in the following types of activities:

#### ***Service Delivery***

- ***Prevention***: This area includes education; information and awareness raising; life skills enhancement; behavior change; action to change harmful traditional practices and cultural or gender norms and to reduce stigma and discrimination; access to safe means of protection (condoms and lubricants, needles and syringes) and their distribution; HIV testing and related counseling; activities targeting groups at elevated risk, in particular, marginalized populations who fear authority and public service because of their illegal behaviors; and activities aimed at preventing mother-to-child transmission (PMTCT) of HIV.
- ***Referral and an increased utilization of services***: Communities serve as an interface between outreach activities and HIV counseling and testing (HCT), treatment, care, and follow-up. The contribution by the community response to prevention is to facilitate access to HCT and is not limited to promoting uptake of services.
- ***PMTCT and treatment***: Communities can play a supporting role in medical care by referral to health facilities, monitoring of HIV and TB treatment adherence, and other activities that complement government response, treatment education, and literacy.
- ***Care and support***: Communities can aid in social, psychological, and spiritual support; counseling; child care, day care, and respite care; home-based care; palliative care; nutrition support; social support, including for orphans and vulnerable children (OVC) and families; support group and self-help activities; and economic support. They can also help ensure adherence to treatment.
- ***Impact mitigation***: Community efforts can positively impact savings and credit, grants, vocational training, income generation, material and welfare support, agricultural support, food assistance, nutrition gardens, legal support and referral, and welfare support and referral.

### **Community Mobilization**

- **Advocacy and networking:** Community mobilization can create demand for services, policy dialogue, and human rights activities, among other needs.

### **Community Organization and Governance**

- **Planning and implementation:** Community activities can include monitoring activities. They could evaluate the types of governance structures (formal and informal) they have put in place and ask, Is the organization made up of volunteers or paid staff, does it have a budget or an advisory group, and does it receive funds that need to be accounted for?

### **Community Financing**

- **Fund raising and financing:** Communities can undertake community-driven financing of an organization's budget; locating funding sources and in-kind contributions; and analyzing how resources are used and who benefits.

**Beneficiaries.** Community responses may also be categorized 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, such as the following:

- People living with HIV
- People affected by HIV, including 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, prisoners, transgender people
- Other vulnerable populations such as people with disabilities, or specific population groups, such as women or youth
- Targeted community groups as determined by culture, or religion
- Local leaders and appointed officials

**Business and opinion leaders.** Communities can play a leading or supporting role: they could provide goods and services directly to the beneficiaries, or they could be facilitators for those services. 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. Community responses tend to play a supporting or complementary role when they facilitate services such as food, HCT, or treatment provided by others groups or the private or public sectors. (See box 5.)

### **Box 5: The role of community responses**

The **Commission on AIDS in Asia** (2008) noted that community participation is critical to successful HIV prevention for people engaged in risk behaviors—studies show that more than 80 percent of drug users could be reached within six months with condoms and cleaning kits through peer outreach workers, whereas interventions relying on local leaders, social workers, and medical staff reached only 25 percent. It also highlighted the importance of community involvement in influencing norms, for example, sex-worker-led safe sex efforts such as in the 100 percent condom use program in Thailand and the Sonagachi project in India.

A study in **South Africa** (M'Zamani et al. 2007) found that 90 percent of community organizations were involved in prevention and 70 percent in care and support. Involvement with treatment was more limited, with a focus on treatment literacy. The emphasis of nonstate actors was on general rather than technical services. Community organizations were more active in care and support—more than 70 percent work with OVC—while government institutions were more active in the delivery of such services as voluntary counseling and testing (HCT) and PMTCT.

The **role of communities in the transport sector** deserves mentioning, in particular the role of unions, which often are involved in the provision of preventive services, both for workers in the transportation business but also for those involved in the construction of roads and other infrastructure projects (International Transport Workers' Federation 2005 and Altaf 2006).

### **3.3. Actors**

The typology 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, including those living with HIV
- Community initiatives, structures, and organizations
- Local, national, sub-regional and regional NGOs, FBOs, and networks
- International NGOs, FBOs, and networks (funding and supporting implementation)
- Multilateral, bilateral, and UN agencies (providing funds)
- National and local governments

A review of World Bank documents and published literature 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.

With respect to the needs of others, Foster (2005) describes small-scale, informal actions by groups of individuals motivated to care for those in need, such as PLHIV and OVC. UNAIDS



(2005) describes a range of community-based care and treatment services emerging across Africa in response to need and filling in gaps in public sector provision of these services.

With respect to an individual's or entity's own needs, a review of PLHIV organizations in Mozambique found that groups directly affected by HIV and AIDS organized themselves as a way of dealing with common problems, sharing difficulties, giving each other practical assistance and emotional support. Community-driven responses cited in the Commission on AIDS in Asia report, 2008 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. Also, being part of the community allows them to interact with sometimes transient populations that may be suspicious of government.

There are examples of community responses initiated by external actors and led by communities. The Sonagachi Project in India supported sex-worker-led efforts to prevent HIV. However, most documented examples are of responses initiated by communities and subsequently supported by external actors (see box 6).

### Box 6: Examples of external support for community-initiated responses

In Malawi, Word Alive Ministries International, a network of congregations, started providing HIV counseling in 1992 and home-based care in 1996. Services have since expanded with funding from the US Agency for International Development and the Canadian International Development Agency. In Zimbabwe, Island Hospice and Bereavement Service, set up to provide care and support for people with cancer, subsequently expanded its services to include care and support for PLHIV with donor funding.

The International HIV/AIDS Alliance uses a “linking organization” approach, where larger national NGOs support community organizations. Examples include (1) Philippines HIV/AIDS NGO Support Program, which has supported Pinoy Plus, a self-help group for PLHIV, to carry out peer counseling and advocacy, and IWAG Dabaw, Inc., a gay organization in Davao City, Philippines to mobilize action among gay men; (2) Instituto para el Desarrollo Humano in Bolivia, which has advocated successfully for comprehensive health care for marginalized and at-risk populations; and (3) L’Initiative Privée et Communautaire contre le VIH/SIDA 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, International Community of Women Living with HIV and AIDS, 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 by or with assistance of external organizations has frequently had the effect of developing informal initiatives into formal community organizations -formalizing systems is usually a prerequisite to accessing external funding -and in expanding the technical capacity, 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 external actors, **donor agencies** have been especially influential in catalyzing and building on community responses primarily through funding. Increased donor funding, in particular from the World Bank, DFID, the Global Fund, and the President’s Emergency Plan for AIDS Relief (PEPFAR), has played a critical role in driving -and setting the agenda for - community responses.

- The World Bank MAP channeled 38 percent of its funding to CSOs, including support for community responses to HIV and AIDS, between 1999 and 2005.

- The Global Fund channeled only 35 percent of resources to *non* CSOs/FBOs. 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.” (Global Fund and International HIV/AIDS Alliance 2008)
- 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. (PEPFAR 2009)
- Beyond these large basket funds, it is also important to acknowledge the large amount of private (including philanthropic) funding that is provided for HIV and AIDS -as well as for example, substantial individual congregational funding is aimed directly to community level projects.

Some authors have questioned the extent to which external funding strengthens local ownership of responses. They suggest that local ownership and agendas may be undermined by decisions to establish “fundable activities” in accordance with priorities set outside the community. M’Zamani et al. (2007) suggest that NGOs and CBOs may be motivated by survival, leading them to tailor their activities to available funding opportunities. Birdsall and Kelly (2005b) highlight the potential adverse impact on the independence and sustainability of civil society that may result from the drive to scale up HIV responses using community organizations as implementing agencies.

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, “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.”

Thus in some countries, accessing external funding may have been a key factor driving community organizations’ responses to HIV, while in other countries, the response was initially mostly 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. In other contexts, purely needs-driven community initiatives

continue with little to no external funding at all, such as the burgeoning community support groups in Lesotho (ARHAP 2006). Further tensions have been highlighted in the role of intermediaries such as international NGOs, suggesting that the transaction costs of such interventions need to be scrutinized carefully (see box 7).

**Box 7: Assessment of large-scale OVC programs administered by international NGOs**

The STRIVE (Support to Replicable, Innovative Village/Community Level Efforts) program for vulnerable children implemented by Catholic Relief Services (CRS) in Zimbabwe during 2001–07 collected data that helps answer important questions about the effectiveness of international NGOs. USAID provided \$2.5 million to CRS for the first phase with the aim of testing innovative interventions that allow resources to reach children at risk quickly and efficiently. CRS provided subgrants to support community efforts to assist children at risk. Subgrants of between US\$147,000 and \$196,000 were provided to “eight local community and faith-based organizations” that supported between 2,800 and 8,000 vulnerable children. Another eight local and international NGOs received subgrants of between \$46,000 and \$649,000. Costs per child-reached varied from \$3 to \$65 per child per year with the highest costs being incurred by international NGOs (CRS 2003, 2004). Two international NGO subgrantees were subsequently dropped from the second phase of STRIVE.

The total cost of the program over five years was \$11 million, of which nearly two-thirds was provided by USAID. The final evaluation found that the approach of making subgrants through a private US voluntary organization was costly, with few resources reaching communities and children. The evaluation concluded that the consequence of this funding approach was an inverted pyramid where resources seemed to dissolve at successive levels, leaving little for actual on-the-ground activities. Most of the subgrant funds were used for operating expenses and community interventions were a “very small—even tiny” component of the total grant (Depp, Maruna, and Yates 2006).

**Other external actors** that have played key roles in community responses to HIV and AIDS include those in the following examples:

- UN agencies -the United Nations Development Programme initiated Community Conversations, an approach that facilitated dialogue in the community. UNAIDS has promoted and strengthened the capacities of civil society organizations to play roles in the national and global response to HIV and AIDS and has been instrumental in the formation and expansion of associations and support groups for people living with HIV.
- International networks and NGOs, i.e. the Naz Foundation International supports MSM networks and groups to establish HIV services.
- Governments -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, external actors provide a range of other support for community responses. These include capacity building and organizational development, technical assistance, and support for networking and coordination. (See box 8.) A UNAIDS (1999) best practice document also highlights the role of lessons learned from experience elsewhere and of international guidance in driving community responses. For example, Cambodia's home care program, 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 8: 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: (1) a private grant-making institution; (2) a CBO mentoring organization; (3) a membership network of groups working with affected children; (4) a small-grants scheme; (5) a provincial health department collaborating with NGOs; (6) an umbrella network for ASOs; and (7) 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.

### ***3.4. Contextual factors***

The country context influences the landscape of community responses. For example, differences in the ways that 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.

Countries and regions have different historical trajectories which have resulted in the development of particular **civil society contexts** and different manifestations of civil society. For example, broad regional similarities have been noted between community-based response to HIV in Anglophone African countries (with greater numbers of associations organized in a decentralized manner, and faith-based groups playing a key role in health care). This can be compared with Francophone (West African) countries which tend to have more compact community-based groups based on standard service delivery models. North African countries in turn tend to have fewer community-based organizations involved in HIV-related activities, likely as a result of a lack of overall community and civil society development (UNAIDS 2005, Schmid et al 2008).

The **epidemic context**, in particular, drives community responses and the types of activities undertaken. In Sub-Saharan Africa community responses are often described in terms of PLHIV and OVC support, whereas in Asia, examples tend to highlight responses driven by group most at risk of HIV infection, such as sex workers and MSM.

Community responses have also evolved as the epidemic has evolved. NGOs working on AIDS issues in Brazil focused initially on fighting social exclusion and pressuring the government to be more responsive. NGO leadership subsequently 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) program 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 characterized by **location**. A mapping of community responses (M'Zamani et al. 2007) in three settings in South Africa -a large urban township, a small town, and a rural area -found very few organizations operating in the rural area. In the rural area, community response, instead, emerged as outreach conducted by churches and home care provided by a local NGO. In contrast, there were 67 and 104 organizations in the town and urban township, respectively, involved in a range of activities. These included support groups, home-based care, spiritual support, condom distribution, and provision of transport to clinics for PLHIV.

Another review of a subset of faith-based organizations in a South African database (Birdsall 2005) found that the nature of services provided by FBOs depended on the setting. FBOs in rural areas were less involved in food programs 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 both 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.

Finally, community responses have been driven by peer-learning facilitated by networks, such as Grassroots Organizations Operation Together in Sisterhood (GROOTS) International, Huairou Commission, Shack/Slum Dwellers International and others.

### ***3.5. Community involvement***

The typology of community responses can also be categorized according to *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, and supported with community resources, to “co-option” of communities by external actors, with various degrees of community consultation, community participation, and community mobilization in between.

A study of PLHIV involvement in community-based programs (International HIV/AIDS Alliance and Horizons 2002) identified a spectrum of five “areas of involvement”: (1) use of services; (2) support of services; (3) delivery of services; (4) planning and design of services; and (5) 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 program called the Community Response to Reducing HIV/AIDS Stigma and Discrimination. PLHIV were involved in program design and implementation and were empowered to advocate for their rights and to gain the support of their communities through community forums. These groups strengthened the capacity of PLHIV organizations.

Informal responses, initiated and led by communities, are an important manifestation of community involvement. As discussed, however, they are not well documented. Most examples in the literature involve an external 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 external 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 (shared norms and social networks), that enable community members to engage in common action.

### ***3.6. Partnerships and collaboration***

Finally, the typology of community responses can be categorized according to the extent to which these responses involve different actors working together within and across sectors, and the different ways in which partnerships and collaboration are structured and managed (see boxes 9 and 10). Networking and partnerships are important elements of community responses, and can be structured in a variety of ways:

- ***Umbrella groups, networks, and coalitions*** -these involve alliances between groups with common interests or activities. Often they are 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. Additionally, networks are increasingly involved in the disbursement of funds to support community-level initiatives.
- ***Formal partnerships*** -these include formal agreements between community organizations and government or other organizations for the delivery of specific services. Formal service-delivery agreements are mostly initiated by external actors including government agencies, international NGOs, and donors. These agreements may be the result of proposals from CBOs approved for funding.
- ***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 organizations have informal links with other organizations on an *ad hoc* basis.

#### **Box 9: Partnerships and collaboration in South Africa**

A community audit in South Africa (Birdsall and Kelly 2005a) found that 88% of CBOs and NGOs and 50% of FBOs network collaborated 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 formal 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.

Partnerships and collaboration can be internally or externally driven. (See boxes 8 and 9.) There is little in the literature concerning factors that enhance or limit partnerships. Birdsall and Kelly (2005b) identified competition between community organizations for funding, clients, 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.

A different study on HIV and AIDS related collaboration between faith-based and secular stakeholders in Kenya, Malawi and the Democratic Republic of Congo (DRC) found many context-specific opportunities and obstacles for partnership, with a complex web of collaborative networks and relationships appearing at local, national, regional and international levels (Haddad et al 2008). It was also noted that these countries can be seen to be in different 'phases' of partnership, with Malawi well entrenched in an 'AIDS Industry', Kenya in a phase of enthusiasm for partnership, and the DRC a post-conflict context where trust and partnership strategies remain tenuous. In all these countries, tensions were expressed with regard to inadequate representation in coordinating structures, and the lack of ownership of agendas. In addition, very different levels of HIV-related partnership can be expected at national and local levels.

#### **Box 10: Examples of collaboration**

##### *Examples of internally driven collaboration*

- In South Africa, the Children's HIV/AIDS Network ensures coordination among over 400 partners, including NGOs, CBOs, communities, home-based caregivers, children's homes, day care centers, FBOs, businesses, unions, academic institutions, health facilities, and government departments of, for example, health, education, social services, and poverty alleviation. (CHAIN 2006).
- 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 collaboration*

- 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. (Haci, n.d.).
- In India, a continuum of care project, initiated by the state government, National AIDS Control Organization (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 as they can often apply flexible, innovative, and cost-effective approach and can reach and work effectively with people at the community level, especially the most vulnerable. NGO involvement is in keeping with the Bank's participation policies. (Garrison and Abreu 2000)

## 4. Documenting the Community-based Response

Community responses to HIV and AIDS can be characterized in many different ways. Six different ways of providing such a characterization have been proposed, dealing respectively with (1) Organizations and structures; (2) Activities and beneficiaries; (3) Actors; (4) Contextual factors; (5) Community involvement; and finally (6) Partnerships and collaboration. Other dimensions could have been considered, and there is no unique way to come up with such a typology. However, in the many studies consulted, one or more dimensions were identified as critical. Still these dimensions of the community response are all important, and should be considered in field work aiming to better document existing community responses.

In Figure 3, sample questions are provided on each of the six dimensions described above in order to facilitate the design of questionnaires that can be used at the community level in order to map existing community actions and activities. This list of questions is not meant to be exhaustive, but it may be useful when aiming to document in a particular context the extent and the characteristics of community responses. These questions are not proposed as a complete research tool, but rather as a frame to ensure that these important dimensions are all incorporated - and would more appropriately be incorporated into existing mapping tools, or developed further, depending on specific research, evaluation or programmatic aims.

For example, in mapping work at the local, national, or sub-national level, it may not be necessary to ask respondents about all existing initiatives -if the main initiatives in terms of size or innovation (for example for pilot programs) can be documented, this would already represent a clear improvement versus a situation in which most of the information that is available is not systematized, and often of an anecdotal nature.

**Figure 3:** Sample Questions for Documenting Community Responses

Typology	Sample questions
<b>1. Organizations and structures</b>	<ul style="list-style-type: none"> <li>• What are the main organizations or initiatives involved in the community response to HIV and AIDS in your community (e.g., community initiative, CBO, NGO, FBO, rights-based organization, mass organization, network, private-sector organization)?</li> <li>• Does the initiative mainly operate locally, nationally, regionally, internationally?</li> <li>• What is the <i>type</i> of community organization or initiative (informal or formal)?</li> <li>• Does the community organization / initiative consider itself to be “faith-based”?</li> <li>• How long has the initiative been implemented in the community and how has its structure changed in this time?</li> <li>• What is the main focus of the initiative (e.g., is the primary focus on HIV or has HIV been added to an existing portfolio of activities)?</li> <li>• What is the organization / initiative’s institutional arrangements and capacity (e.g., mission, management structure, membership, governance, systems for planning,</li> </ul>

Typology	Sample questions
	<p>finance and M&amp;E, implementation approach, paid staff and volunteers)?</p> <ul style="list-style-type: none"> <li>• What are the organizations / initiative’s budget, funding sources, and funding channels (direct or through an intermediary)?</li> <li>• How dependent is the organization’s work on external funding?</li> </ul>
<b>2. Activities and beneficiaries</b>	<ul style="list-style-type: none"> <li>• What are the main areas of activity (e.g., prevention, treatment, care and support, impact mitigation, advocacy, networking, research, community mobilization, fund raising,) and specific activities and services provided?</li> <li>• What is the scale and reach of activities?</li> <li>• Does the organization play a leading role or a supporting or enhancing role in different areas of activity?</li> <li>• Have activities evolved over time (e.g., in response to external actors, availability of funding, or local need)?</li> <li>• Has geographical coverage evolved over time (e.g., in response to external actors, availability of funding, or need)?</li> <li>• Who is the target audience (e.g., the whole community or specific target groups)?</li> <li>• What is the perception of beneficiaries about the quality of services provided? Is there data to assess the quality of the services provided?</li> </ul>
<b>3. Actors</b>	<ul style="list-style-type: none"> <li>• Was the initiative 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)?</li> <li>• Have the drivers changed (e.g., the response was initiated by communities but subsequently supported by external actors)?</li> <li>• Who leads the initiative (e.g., initiated and led by community, initiated and led by external actors, or initiated by external actors and led by the community, volunteers or paid staff)?</li> <li>• Do the community-based activities receive external support?</li> <li>• If so, what are the sources of external support (e.g., donor agency, UN agency, government, international NGO, national or local NGO, private sector, faith-based or not)?</li> <li>• How has external support influenced the community response?</li> <li>• 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?</li> <li>• When did external support start and what is the duration of external support?</li> <li>• What monitoring and evaluation do you undertake, and do you have lessons to share about how effective responses can be managed?</li> </ul>
<b>4. Contextual factors</b>	<ul style="list-style-type: none"> <li>• How have political, cultural, social, and economic contexts influenced the community response?</li> <li>• How has the epidemic context influenced the community response?</li> <li>• Have activities changed as the epidemic or the national response to it has evolved?</li> <li>• How has the location (e.g., urban, rural) influenced the community response?</li> <li>• How have the organization’s activities been influenced by national plans?</li> <li>• How have the organization’s activities been influenced by local or district-level plans or strategies?</li> </ul>

Typology	Sample questions
<b>5. Community involvement</b>	<ul style="list-style-type: none"> <li>• To what degree is the community involved (e.g., community leads, actively participates, supports, is informed, is co-opted)?</li> <li>• What activities or interventions are the community involved in (e.g., identifying problems, needs, and priorities; planning and design; implementation and service delivery; M&amp;E)?</li> <li>• Has the involvement of the community been sustained over time? (e.g., ongoing relationship, occasionally involved, or once-off consultation)</li> <li>• To what degree are target groups or intended beneficiaries involved?</li> <li>• What are the characteristics of the community (e.g., incentives, capacity, skills, and social capital, i.e., shared norms and values and social networks)?</li> </ul>
<b>6. Partnerships and collaboration</b>	<ul style="list-style-type: none"> <li>• How are the organization's activities linked to community organizations?</li> <li>• How are the organization's activities linked to and aligned with government services (e.g., local government, local AIDS committees, health facilities, social welfare services, and health, education or justice departments)?</li> <li>• Are referral systems in place between the community-based organizations and service providers?</li> <li>• What partnership arrangements are in place (e.g., formal partnerships and memorandums of understanding, informal partnerships, collaboration or shared networks)?</li> <li>• How do actors in the community participate in coordination mechanisms, networks, umbrella organizations, or coalitions?</li> <li>• Which actors are driving partnerships and collaboration (e.g., internally or externally driven)?</li> </ul>

Source: Authors.

It must be emphasized that some questions are more sensitive than others and some consideration is necessary prior to the implementation of these questions in a community setting. For example, the leaders of some community-based interventions may not necessarily be willing to release financial information, especially to persons or groups that are external to the community if trust has not been established beforehand. For other questions, such as those related to the quality of the services provided by community activities, good data may be missing, and subjective perceptions by those who run the community responses are likely to be biased. In many cases, monitoring and evaluation (M&E) systems are likely to be missing, but it may still be useful to know whether those who implement the community response would support such M&E efforts.

One key question is whether community responses are well integrated into (and benefit from support from) district or national level efforts to respond to the HIV and AIDS epidemic. Most existing studies aiming to map community responses to HIV and AIDS suggests that these responses often have limited engagement with broader efforts, sometimes because the national campaigns may not trickle down up to the level of specific communities. Indicators as

to the length and sustainability of community engagement are also important – it is not uncommon for some external NGOs to come and go, so that after once-off participatory consultations have been conducted and some initiatives launched, the ability to pursue such activities is weakened. Typically, when the initiative is launched by local groups, many of which have a faith affiliation, the likelihood of sustainability is higher.

While the sample questions provided in Figure 3 may provide a good starting point when planning field work in order to document community responses to HIV and AIDS (or other issues), further work will be needed to refine these questions and the correlate indicators as we work towards a systematic evaluation of community response that is inclusive of the inherent and characteristic complexity of this response.<sup>6</sup>

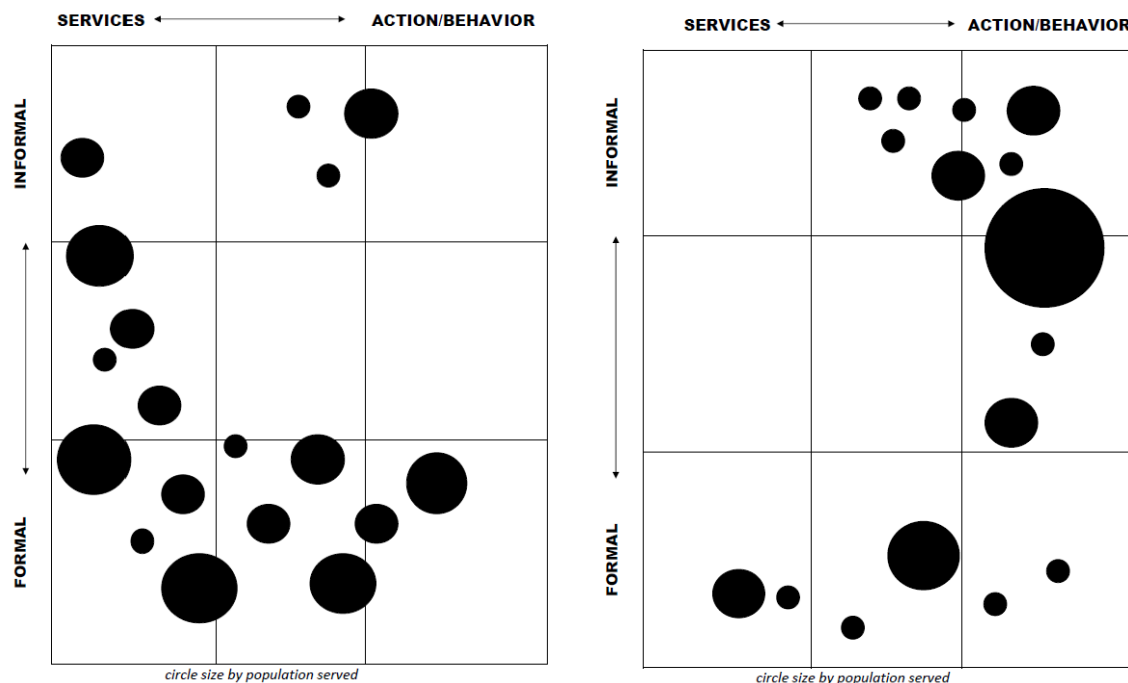
Certainly more consideration will need to be given to how complex and context-specific community responses can be represented and communicated to policy makers – and therefore how the six dimensions of this typology can be simplified and represented, without losing valuable content.

An example of such simplification is provided in Figure 4 adapted from Olivier and Wodon (2010). The basic idea behind Figure 4 is that from the point of view of a policy maker aiming to understand existing interventions related to HIV and AIDS, some of the most important questions refer to (1) who is providing services or benefits, and (2) what services or benefits are being provided. These two dimensions are close (but not identical) to the “organizations and structure” and “activities and beneficiaries” dimensions of the framework presented in the previous section, although they also factor in some other aspects of the typology presented above.

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<sup>6</sup> As mentioned above, this paper represents a first-stage framing of a larger systematic evaluation effort.

**Figure 4:** Mapping Community-Based Interventions on HIV and AIDS



Source: Olivier and Wodon (2011).<sup>7</sup>

The matrices provided in Figure 4 are hypothetical and illustrative as to the type of analysis that can be done and visualized for policy makers –the matrices divide information gathered from a field mapping exercise using the typology, presented in this paper into first, on the vertical axis, the types of organizations that are providing services. These organizations may be formal, informal, or a combination of formal and informal groups and entities. Next, on the horizontal axis, the kinds of activities that the community-based interventions are engaged in are classified. These activities may range from services such as treatment, care and support services, to activities which impact (often indirectly) on actions, for example those aimed at changing behavior, attitudes and perceptions related to HIV and AIDS. Based on what we currently know, community-level responses can frequently combine elements of service delivery and impact on action and behavior which can be depicted along such a spectrum. For example, formal prevention-focused behavioral change interventions targeted at communities by government health departments, and informal faith-based congregational abstinence initiatives that carry potential for similar or related action.

Different community activities could thus be mapped onto the 3x3 matrix. Typically each activity would be represented by a circle whose size would be proportional to the number of

<sup>7</sup> These matrices are constructed examples intended for demonstration and are not representative of a particular country or community.

people reached, or the cost of the activity, or the likely impact of an activity on development targets if that is feasible. Based on the qualitative research that has been done, we can expect that in one community context, the matrix might look very different from what is going on in another community. Different colors can also be used to represent activities benefiting from government support, as compared to activities that do not benefit from such support, or urban-rural service allocation.

The visualization is simple, but such methods can help in identifying weaknesses, strengths and gaps in various areas of the community response, identifying areas of overlaps, and more generally in re-orienting resources in order to achieve higher overall impact. Importantly, such visualizations quickly make apparent the inadequacy of data which focus only on community response emerging through formal mechanisms (organizations and structures) – and adds urgency to the agenda which seeks to understand and evaluate informal community responses, without destroying them in the process.

## 5. Conclusion

This paper has provided a basic operational typology for the analysis of community responses to HIV and AIDS – which can be characterized in six main ways (1) Organizations and structures; (2) Activities and beneficiaries; (3) Actors; (4) Contextual factors; (5) Community involvement; and finally (6) Partnerships and collaboration. This typology can be used for other characterization, for example, to describe community support of health systems. Given the inherent variety of existing community responses, and the inadequacy of many of the current research frameworks and tools to properly capture this complexity well, the sample questions provided in the paper (in Figure 3) as well as visualization tools (as in Figure 4) may help community-based organizations and those supporting them in documenting more systematically existing interventions.

The framework provided here is not meant to be in any way an absolute reference. A number of previous studies have undertaken to *map* and assess the community level response to HIV and AIDS, working to blend participatory community research with the quantitative typologies and measures necessary for mapping work (ARHAP 2006). These ‘deep-dive’ studies have shown a complex local reality, where international organizations, government programs and local community initiatives (of all shapes and forms), work in rural and urban communities – often in ways we do not expect.

Today we know significantly more than we did a decade ago about semi-formal and formal initiatives on HIV and AIDS such as those run by NGOs or public health facilities -these are also the initiatives that receive the most support, which in turn results in the establishment of more

initiatives of these kinds by civil society organizations. But it remains a much greater challenge to understand and assess the “lower level” of community initiatives -for example women’s groups working out of congregations with or without the knowledge of their religious leader; informal community support groups that function with no external funding (as is the case in Lesotho); or innovative community initiatives where AIDS patients are being bicycled to the local hospital each week for treatment by an organized community group (as is the case in Zambia) (ARHAP 2006). There remain thus important challenges to our research strategies and tools to be able to adequately map (in terms of understanding, and not only locating) and support such initiatives without destroying them or reshaping them by imposing too rigid research frameworks on them. This also implies that typologies for community response need to be multi-disciplinary, sensitive to creative and innovative responses, and integrative of different data streams. There is constant tension in this work in getting right the balance between qualitative, context-rich information which can describe different formations of community response, and systematic quantitative assessments, which require some standardization of language, label and typology. A typology is ultimately a tool to help understand communities and community activities.

Overall, it is probably often not possible, and perhaps even not that useful, to suggest what a “typical” community response is, not to speak of what it could or should be. The richness of the community response may very well be in its multiple combinations and its variety -its uniqueness in the community’s cultural and geographic context. At the same time, for policy makers, some systematization and simplification is useful in order to suggest broad tendencies, and come up with diagnostics of the strength and potential weaknesses of existing responses. In terms of final “take-home” messages, the following can be emphasized:

- ***Community responses to HIV and AIDS involve a wide range of actors, encompassing informal and formal organizations and structures.*** The contribution and activism of those living with HIV has been especially valuable. This diversity represents a challenge for the evaluation of community responses. Available evidence about community responses is based largely 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, such as PLHIV or OVC;*** to respond to their own needs, as with MSM; or respond to issues driven by external actors. External actors and funds have played a critical role in catalyzing, strengthening, 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 all aspects of the HIV response and in all contexts.*** These responses could include advocating for access to services, providing care and support for those most affected by the epidemic, assisting in the development of policy and strategy, and organizing peer efforts among marginalized populations. Community responses can also provide support to government services by encouraging uptake of HIV testing, challenging stigma and discrimination, and supporting treatment adherence. In certain circumstances, community responses can also challenge the scope and reach of government actions.
- ***Community responses demonstrate a range of community involvement and typologies*** for partnerships and collaboration with other actors. Community responses that work in partnership or collaboration 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 the response; (2) The types of activities and services implemented and the beneficiaries of these; (3) The actors involved in and driving community responses; (4) The contextual factors that influence community responses; (5) The extent of community involvement in the response; and (6) The extent to which community responses involve wider 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 design or programs as much as the evaluation of community responses.
- ***The Operational Framework can be applied to map or describe the typology of community responses to different problems in different settings; to inform analysis of community responses; and to support further analysis*** -for instance, of the factors that make community responses effective. The strength of this approach is that it would allow informal community responses to be documented that might not be captured

using other approaches. Its added value is that it provides a systematic approach to understanding complex situations.

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## Annex: Contributions and Consultative Process

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