

COMMUNITY MOBILIZATION TO MITGATE THE IMPACTS OF HIV/AIDS

Displaced Children and Orphans Fund

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Introduction

The HIV/AIDS pandemic is unraveling years of hard-won gains in economic and social development. The scale and severity of the social and economic impacts of the pandemic, already large, will continue to increase for many years. By next year in five countries, an estimated one of every four children will be orphans, and the proportion will be one in five in an additional four countries, with others not far behind. Life expectancy will drop to 40 years or less in nine sub-Saharan Africa countries by 2010, and AIDS-related mortality will substantially reduce gains made in child survival in many countries. HIV/AIDS is not only an increasing cause of death among adults, infants and young children, it is also slowly impoverishing and dismembering families, leaving growing numbers of orphans in its wake. At all stages of the epidemic, families bear most of the social and economic consequences of HIV/AIDS. The pandemic is an evolving, slow onset disaster, and no country can assume it has seen the worst of it.

Community Mobilization and HIV/AIDS Impact Mitigation

Families and communities make the most important responses to the impacts of HIV/AIDS. Not only are they on the front line of the impacts of HIV/AIDS, they *are* the front line of response to the health and welfare problems caused by the epidemic. Communities are not only concerned about the impacts of HIV/AIDS, but also prepared to take leadership, demonstrate ownership and devise ways of sustaining the activities they initiate. They are *the* key stakeholders.

In the developing countries most heavily affected by HIV/AIDS, a majority of development activities dealing with mitigating the disease's negative consequences has fallen into two categories:

- NGO programs whose paid staff deliver direct relief and development services to affected children and families, sometimes using trained community volunteers. Many of these have produced good results, but with relatively limited

In Malawi and Zambia, community members are alarmed at the number of children who have lost one or both parents to AIDS. They are also concerned about households who are unable to provide food for themselves because they are either caring for an ill family member or are sick themselves. Many concerned individuals visit such neighbors and help out by running errands, taking care of children or assisting in household chores. In both Zambia and Malawi, members of church groups also do what they can to ease the burden on households affected by the impacts of HIV/AIDS.

geographic coverage and a cost per beneficiary too high to reach more than a tiny fraction of families and communities made vulnerable by HIV/AIDS; and

- Community-based initiatives that have produced good results at a low cost per beneficiary but whose geographic coverage have also been very limited.

The foundation of an effective response is to strengthen the capacities of families and communities in the geographic areas where HIV/AIDS has made them especially vulnerable. If community-based projects grounded in participatory development techniques can be scaled up effectively, then this approach may provide a cost-effective, sustainable way to address the crisis.

Features of Successful Community Mobilization

The process of mobilization must start with a community identifying its own concerns. A recurring theme among communities seriously affected by HIV/AIDS is their concern about the growing number of orphans and vulnerable children and the circumstances in which they live. Communities often rally around activities designed to provide care for such children and support to their guardian households. The motivation that energizes their efforts comes from a variety of sources: compassion, religious commitment and a recognition that unless they support each other while they are able, they will have no one to depend on if their own families some day need help.

In Zambia, people in neighborhoods of urban slum areas were also concerned about the impact that AIDS was having on the children in their community. Project Concern International introduced “participatory learning and action” to these communities. As a result, individuals saw their concerns about children not able to go to school echoed by nearly everyone. They joined forces to start community schools.

Community groups that are able to mobilize the entire community’s involvement in carrying out activities become the most dynamic and are able to sustain motivation over the long run. A group that assumes responsibility for addressing problems on behalf of its community is likely to burn itself out.

Although practitioners may use different participatory tools and the issues around which they mobilize communities vary, the process is similar. Whatever the techniques, it is extremely important that organizations observe rigorous standards of excellence in participatory methodology.

What follows below are critical steps in the process of genuine community mobilization:

- recognition on the part of community members that they are already dealing with the impacts of HIV/AIDS and that they can be more effective if they work together (“we need to support each other to deal with this”);
- the sense of responsibility and ownership that comes with this recognition is the starting point for identifying what responses

Save the Children/Malawi’s COPE staff engaged community members in a participatory process to analyze the impact of HIV/AIDS on them. They found that everyone shared concerns about the children of relatives and friends who had either died or were sick. A sense of urgency and the need to join forces to find solutions motivated them to form a committee. They took turns visiting the most vulnerable households, paying particular attention to the children within them. The committee initiated fund raising activities so they could provide food or soap to the most needy of the families. They were able to provide school supplies or help with school fees for some of the orphans.

- are possible: (“this is happening to us so it’s up to us to do something about it”);
- identification of internal community resources and knowledge, individual skills and talents (“who can, or is already doing what, what resources do we have, what else can we do”);
 - identification of priority needs (“what we’re really concerned about is...”)
 - community members planning and managing activities using their internal resources; and
 - increasing capacity of community members to continue carrying out their chosen activities, to access external resources once internal means are exhausted, and to sustain their efforts over the long term.

This process does not happen all at once or necessarily in this order. External organizations act as catalysts to achieve this ownership using participatory processes. They are facilitators, not

The COPE program has been effective in mobilizing communities at health catchment area and village levels. COPE staff are viewed in communities as part of the district and/or community level committees and not as officials from an NGO. The role of the health catchment area and district committees is to facilitate the access of villages to external resources. They have linked village committees to agricultural extension agents who provide advice for communal gardens that produce food for vulnerable families, and revenue to finance committee activities.

managers; capacity builders not direct service deliverers. One of the more subtle challenges for a catalyst is to recognize when a community is ready for which kinds of training and external support, when to link with outside groups, and what resources to tap. A fundamental tenet of community mobilization is that the impetus for action emerges from the community level and the catalyst formulates its agenda around community priorities, concerns, capacities and commitments.

Structures through which mobilization occurs vary among community-based models. However,

community ownership and management of these responses to the consequences of HIV/AIDS are the key features of success.

Community mobilization is a mechanism to define and put into action the collective will of the community. The following are some key guidelines for successful mobilization:

- Once mobilized, a grassroots group should try to engage the entire community in responding to its own shared concerns.
- Community mobilization should not be seen as a way for an outside agency to achieve community consensus around its goals.
- Outside support seeks to build capacity of communities, rather than delivering services themselves. The catalyst role is to sensitize, mobilize and build capacity. Outsiders can catalyze the process in a somewhat systematic fashion, but neither they nor funding bodies cannot dictate what specific actions a community eventually decides to undertake without undermining ownership and, with it, sustainability.
- Let the process unfold according to an internally defined rhythm where the community is left to progress at its own pace. Emphasis is on a process that is iterative and incremental. Taking time, as well as timing of outside support is

Staff of Zambia's Project Concern International work closely with district social welfare agents employed by the Zambian government social services department. They, along with local NGOs, CBOs and church groups are the catalysts that mobilize neighborhood committees. They have assisted poor neighborhoods to gain Ministry of Education recognition for their community schools, approval for their syllabus and training for their volunteer teachers

crucial. Leading with outside resources before a community begins to take action through internally produced means is a sure way to subvert local ownership and responsibility.

Other issues related to HIV/AIDS impact mitigation projects

Scale and sustainability—In the most-affected countries, the scale of the impacts of HIV/AIDS are far too large, varied and interrelated for any single organization, government, international body, or NGO to address unilaterally. Coordination and collaboration are essential among all relevant actors. HIV/AIDS is a development issue, not just a health issue. Cost-effective, sustainable interventions must be expanded to produce sustainable impacts on the same scale at which problems are occurring.

Linking care and prevention—The care and support of people living with AIDS should be linked closely with efforts to mitigate economic and psychosocial impacts. The potential links between care and prevention activities deserve much greater attention than they have received. Programs targeting prevention often operate in isolation from those providing care for people living with AIDS, orphans, and others made vulnerable by the epidemic. Such links might be important in reducing the spread of HIV, since poverty generates a sense of powerlessness and fatalism and a feeling that the things that affect people are beyond their control. This undermines commitment among the poor to heed prevention messages.

The FOCUS Program in Mutare, Zimbabwe, has mobilized volunteers to visit orphans regularly, monitor their situation, respond as possible with community resources, distribute small amounts of externally-provided material support, and refer urgent problems to government authorities. Some 4,000 orphans benefit from the program, and the cost per child visited is about US\$3 per year. Its 1998 budget of US\$13,800 broke down as follows: 44 % material assistance; 7% volunteer allowances and uniforms, 5% volunteer training and meetings, and 44% salaries of the Coordinator and Assistant Coordinator and administrative costs. Efforts are underway to increase program efficiency by integrating orphans visiting with home-based care and HIV/AIDS prevention activities.

A presenter at the 1997 conference of the Malawi Network for AIDS said, “The assumption that people have the will and power to want to change is linked to loving oneself and others, and hope for the future. In the absence of all these, the willpower to change is never there. For people to change they should have hope.”

Similarly, in one of the main presentations at the 1997 regional HIV/AIDS conference in Abidjan, Dr. Alan Whiteside presented his view that higher levels of social cohesion within a country tend to reduce the rate of HIV’s spread. He said, “Many of the HIV and AIDS interventions [in Uganda] may have contributed to slowing the epidemic--not because they were about AIDS, but because they were about building civil society and taking responsibility.”

Empowerment that comes with effective community mobilization reinforces a sense that participants can affect the circumstances of their lives. This awareness may increase receptivity to adopting behaviors that reduce risk of HIV infection.

Personal involvement in community-based care efforts raises participants’ awareness of HIV/AIDS and provides opportunities for program staff to discuss with them how HIV is transmitted and how it can be prevented. In addition, responding to the difficulties of orphans and widows may motivate community residents to avoid risky behaviors that could ultimately have similar consequences for their own families.

Intersectoral partnering—Since families and communities affected by HIV/AIDS are the front line of response to the impacts of the pandemic, programs must be designed to make sense within the realities of their lives. The relevance and effectiveness of programs can suffer where their funding, approaches, and expertise separate them into such boxes as: HIV prevention, voluntary testing and counseling, home-based care for people living with AIDS, care and protection of orphans, and income-generating activities. People living with or affected by HIV/AIDS do not segment their lives in this way, and better integration within and among programs can improve the interventions.

Challenges

The challenges of community mobilization tend to coalesce around two issues: (1) how to scale up operations to match the scope of the HIV/AIDS epidemic; (2) how to sustain community mobilization over the long run. The following examples illustrate these issues.

Keeping ownership alive at community level -- In its five years of operation, the FOCUS program in Mutare, Zimbabwe, has lost only one volunteer, and when she left, there were many more requests to fill the vacancy than the program could accommodate. In 1998 the program had 138 volunteers. The sense of community ownership and responsibility for the program is strong, and volunteers are selected by their community. Programs are usually church-based. Incentives volunteers receive include monthly bus fares to meetings; a tee-shirt, skirt, training shoes and scarf once per year; and an annual Christmas bonus of US\$10. Volunteers receive initial and monthly training. Some make exchange visits to other programs. Volunteers who look after orphans in their own homes may receive small amounts of material support (an average US\$11 per year).

Achieving long-term sustainability -- The first ingredient in the formula for sustainability is generating and continually reinforcing a strong sense of ownership and responsibility among those carrying out activities. Another is identifying, engaging, and developing a community's own skills and resources. Finally, learning how to tap external resources when needs go beyond internal capacity is crucial. There is also a need to find ways of generating a sustainable source of financing to support the community's activities. In response to this last aspect, many community groups choose to start businesses. Unfortunately, these communal enterprises are notoriously risky endeavors; they generally do not generate significant profits and often fail altogether. They frequently require technical or management skills not available within the community. In addition, the time and effort necessary to manage a business successfully takes community members away from the very activities the business is meant to finance. Some communities have had success putting such a business in the hands of a qualified manager.

Systematically mobilizing communities throughout a large area -- The structure of a community mobilization program in Malawi is based on three levels of actors (district, health catchment area, village). Initially, the NGO acting as catalyst mobilized effective action at health catchment and village levels. When it began to work in another area, it started at the districts level, intending to start a "cascade" effect (i.e.; district-level participants mobilize health catchment areas, which in turn mobilizes villages). However, the NGO found that beginning the process further from the village level did not generate sufficient ownership and commitment to make the cascade work effectively, and staff are reassessing how to scale up effectively.

Strengthening Household Economic Resources -- HIV/AIDS is having profound economic impacts at family and community levels. Communities have been mobilized to provide assistance to their most destitute members, but how can these efforts be sustained over time and how can the number of households slipping into destitution be kept to a minimum? The most encouraging approach to shoring up household resources and, thereby, strengthening community resources, are state-of-the-art microfinance programs. Yet this type of program is extremely challenging to implement. To design and manage a community mobilization initiative and deliver microfinance services requires specialized expertise and a focus on these activities. The best option for a group with expertise in community mobilization is to work in partnership with specialized microfinance organization.

Some microcredit practitioners have taken the position that communities seriously affected by AIDS are not likely to be acceptable risks for the provision of credit. Experience suggests otherwise. In Uganda, FINCA's village banking program started in 1992 with USAID and DCOF funds. The program has worked well in communities seriously affected by HIV/AIDS. Its repayment rate is 99 percent, and a recent inquiry found that 75 percent of the participants are caring for orphans. FINCA also operates in parts of Malawi's Southern Region which have been seriously affected by AIDS, yet its program has grown even faster than the one in Uganda and has the same repayment rate.

Free goods -- Many organizations working in poor countries feel that they must supply funds to evoke community participation in their projects. However, it is unclear whether external grants to communities are an effective way to support responses to the impacts of HIV/AIDS. While external funding may help to stimulate efforts, it runs the risk of compromising them by diluting community ownership. It can also instill dependency and an atmosphere of paternalism that stifles community participation and eventually snuffs out motivation or shifts it from addressing the problems at hand to obtaining the funds. Initiating a community mobilization effort by offering free goods as an incentive is a sure route to failure. On the other hand, a community can exhaust all its own resources. When this happens, they can become demoralized and overwhelmed. A modest and carefully timed injection of external resources would make a significant positive impact. Striking a balance between creating dependency and arriving at despondency requires a skillful and thoughtful program approach and regular communication with people in the community.

Responding to village driven needs -- Many agencies specialize in a particular technical area. This often means that the nature of community and village-level activities ends up reflecting an NGO's specialization more than the beneficiaries' needs. Yet, people living with or affected by HIV/AIDS do not segment their lives according neatly defined technical sectors. They must be the ones to identify issues and set priorities.

Monitoring and evaluation that is sensitive to community ownership and need for information, yet complies with donor requirements -- In Malawi, one community had successfully identified indicators that were compatible to donor requirements. The NGO began presenting these indicators as a "package", to other villages. This by-passed the process in other communities who consequently felt as if this package was imposed on them. Communities ceased to gather information and behaved as though the information was now "owned" by the NGO.

Guidelines for Catalysts and Donors

Collaborate in cost-effective strategies

The problems caused by HIV/AIDS are too great for any government, donor, or organization to be effective as a unilateral actor. Just as people are doing on the front line in affected communities, donors and those who would intervene must define common strategies and collaborate closely. They must also give much more serious attention to cost-effective strategies and interventions. Fundamental strategies include building the capacities of :

- families to care for vulnerable children.
- communities to support vulnerable children and households.
- children affected by HIV/AIDS to support themselves and younger siblings.
- the government to protect vulnerable children and provide essential services.

Build an enabling environment

Find ways to make it easier for vulnerable families and communities to cope. This includes increasing the awareness and commitment of leaders and the public concerning children who are especially vulnerable, establishing laws and policies that protect children and widows, reducing stigma and discrimination associated with HIV/AIDS; monitoring the epidemic's impacts and the effectiveness of interventions; and increasing awareness, effectiveness, and coordination among key government bodies, international organizations, donors, NGOs, and CBOs,. In addition, governments have critical roles to play in the protection and placement of children who are abused or neglected, establishing and monitoring compliance with policies to guide action, and delivering such essential services as health care, education, and access to clean water.

Work through organizations that already exist in communities

Considering scale, cost, and potential sustainability, there are advantages to working through organizations or structures already active in a community. Examples include churches and other religious bodies; health services; neighborhood health committees; schools; civic organizations; women's associations; and cooperatives.

Promote state-of-the-art participatory development techniques

Skill in participatory techniques that spark genuine community ownership cannot be acquired by reading a book, or by a one-shot training workshop. While these may help, mobilization is learned through participation, observation, and dialogue. Just as the process itself is iterative and incremental, so too is the development of participatory skills for mobilizers. This takes patience and commitment, but once a foundation of genuine community ownership is established, progress is often very rapid. In addition to developing their own skills, catalysts must also strengthening mobilization and participation skills at the community level.

Creating design and methodological innovations to scale up project outreach

In order for community mobilization programs to scale up, there must be effective links between communities and external structures and resources. Catalysts (whether NGO or extension agents) must promote genuine commitment to the participation from the community level up through each higher level of administration and organizational coordination. Financing training activities may be even more important than providing external grants for project operations.

Training can include enabling more experienced community members to take part in mobilizing and training counterparts from neighboring areas and to exchange lessons with them. Similarly, ensuring that there are periodic “retreats” during which staff review and analyze their progress will allow them to better identify their support needs and plan future strategies.

Promote a two-pronged technical assistance approach

Strengthening household economic resources and community safety nets are two critically important aspects of HIV/AIDS impact mitigation. Since the two types of services involved—microfinance services and community mobilization around HIV/AIDS care and support issues—require specific expertise, it is preferable to involve an organization that specializes in microfinance services along with those with expertise in generating and supporting community-based action around HIV/AIDS and children's issues. Although the two technical approaches should be operationally separate, they must be *conceptually* joined. Recommended areas for joint planning would be (1) the desired impact of microcredit, (2) monitoring and evaluating impacts, and (3) packaging loan products to reach target clients.

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