

**COMMUNITY MOBILIZATION
TO MITIGATE
THE EFFECTS OF HIV/AIDS**

September 1, 1999

*Jill Donahue
John Williamson*

The evaluation report was conducted under the auspices of the United States Agency for International Development. The evaluation was conducted by the Displaced Children and Orphans Fund & War Victims Fund Contract (CRN-C-00-98-0037-00). The opinions expressed are those of the author and do not necessarily reflect the views of the U.S. Agency for International Development or Professional Resources Group International, Inc.

Additional information or copies of this report can be through
The Displaced Children and Orphans Fund website:
<http://www.displacedchildrenandorphansfund.org>

CONTENTS

List of Acronyms.....	v
Map.....	vii
Introduction.....	1
Community Mobilization and HIV/AIDS Mitigation.....	3
Features of Successful Community Mobilization.....	4
Related Issues.....	6
Challenges.....	9
Ownership at the Community Level.....	9
Long-Term Sustainability.....	9
Systematic Mobilization.....	10
Strengthening Household Economic Resources.....	10
Free Goods.....	10
Village-Driven Needs.....	11
Monitoring and Evaluation.....	11
Guidelines for Catalysts and Donors.....	13
References.....	15

LIST OF ACRONYMS

CBO	community-based organization
COPE	Community-Based Options for Protection and Empowerment
DCOF	Displaced Children and Orphans Fund
FINCA	Uganda Women’s Finance Trust and Foundation for International Community Assistance
FOCUS	Families, Orphans, and Children Under Stress
HIV/AIDS	human immunodeficiency virus/acquired immune deficiency syndrome
NGO	nongovernmental organization
USAID	U.S. Agency for International Development/United States Agency for International Development

INTRODUCTION

The HIV/AIDS pandemic is unraveling years of hard-won gains in economic and social development in sub-Saharan Africa, and the scale and severity of the pandemic's effects, already large, will continue to increase for many years. By the year 2000 in five countries, an estimated one of every four children will be orphans, one in five children will be orphaned in an additional four countries, and other countries are not far behind. Life expectancy will drop to 40 years or fewer in nine sub-Saharan African countries by 2010, and AIDS-related mortality will substantially reduce gains made in child survival in many countries. HIV/AIDS not only increasingly causes death among adults, infants, and young children but also slowly impoverishes and dismantles families, leaving growing numbers of orphans in its wake. At all stages of the disease, families bear most of the social and economic consequences. The pandemic is an evolving, slow-onset disaster, and no country can assume the worst has yet been seen.

COMMUNITY MOBILIZATION AND HIV/AIDS MITIGATION

Families and communities make the most fundamental responses to the consequences of HIV/AIDS. They experience firsthand the effects of the disease itself as well as the health and welfare problems caused by the epidemic. Communities not only are concerned about the effects of HIV/AIDS but also are prepared to take leadership, demonstrate ownership, and devise ways of sustaining the activities they initiate. They are the key stakeholders in fighting the consequences of HIV/AIDS.

In the developing countries most heavily affected by HIV/AIDS, most development activities that are designed to mitigate the disease's negative consequences fall into two categories: (1) programs sponsored by nongovernmental organizations (NGOs) and (2) community-based initiatives.

In NGO programs, paid staff members deliver direct relief and development services to HIV/AIDS-affected children and families, sometimes using trained community volunteers. Many of these programs have produced good results, but they have relatively limited geographic coverage and a cost per beneficiary that is too high to reach more than a tiny fraction of families and communities made vulnerable by HIV/AIDS.

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 whose members are unable to provide food for themselves because they are 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, church groups also do what they can to ease the burden on households affected by HIV/AIDS.

Community-based initiatives have produced good results at a low cost per beneficiary, but their geographic coverage has also been very limited. The foundation of an effective response is the strengthening of the capacities of families and communities in the geographic areas where HIV/AIDS has made them especially vulnerable. Community-based projects grounded in participatory development techniques, if they can be scaled up effectively, 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 those children live. Communities often rally around activities designed to provide care for such children and support to their guardian households. The motivation that energizes community efforts comes from a variety of sources: compassion, religious commitment, and a recognition that unless community members support each other while they are able, they will have no one to depend on if their own families someday need help.

Community groups that are able to mobilize the entire community in carrying out activities become the most dynamic and are able to sustain motivation for an extended period. A group that assumes responsibility for addressing problems on behalf of its community is not likely to sustain itself.

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.

Following are the critical steps in effective community mobilization:

- Experiencing recognition on the part of community members that they are already dealing with the consequences of HIV/AIDS and that they can be more effective if they work together (“We need to support each other to deal with this problem.”)
- Assuming a sense of responsibility and ownership that comes with the community’s recognition and that is the starting point for identifying what responses are possible

In Zambia, people in neighborhoods of urban slum areas were concerned about the effect that AIDS was having on the children in their community. Nearly everyone in the community voiced the concern about children not being able to go to school. Project Concern International introduced “participatory learning and action” to these communities. Members of the community joined forces to start community schools.

Save the Children/Malawi’s Community-Based Options for Protection & Empowerment (COPE) staff engaged community members in a participatory process to analyze the effect of HIV/AIDS on the community. They found that everyone in the community shared concerns about the children of relatives and friends who either had died or were sick. A sense of urgency and the need to join forces to find solutions motivated the community members to form a committee. They took turns visiting the most vulnerable households, paying particular attention to the children within them. The committee initiated fundraising activities to provide food or soap to the neediest families and furnished school supplies or helped with school fees for some of the orphans.

(“This problem is happening to us, so it’s up to us to do something about the problem.”)

- Identifying internal community resources and knowledge as well as individual skills and talents (“Who can do what, or who is already doing what?” “What resources do we have?” “What else can we do?”)
- Prioritizing needs (“What are we most concerned about?”)
- Having community members plan and manage activities with their internal resources
- Increasing the 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

The COPE program has been effective in mobilizing communities at the level of health catchment areas and villages. Communities view COPE staff as part of the district- 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. COPE staff members 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.

The process to mobilize communities does not happen all at once or necessarily in the order in which the steps are listed above. External organizations act as catalysts to promote ownership through participatory processes. They are facilitators, not managers, and 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 communities. However, community ownership and management of these responses to the consequences of HIV/AIDS are the key features of success. Community mobilization, which is a mechanism to define and put into action the collective will of the community, depends on the following guidelines for success:
- Once mobilized, a grassroots group should try to engage the entire community in responding to its particular shared concerns.
- Community mobilization should not be seen as a way for an outside agency to achieve

Staff of Zambia’s Project Concern International work closely with district social welfare agents who are employed by the Zambian government social services department. Those individuals, along with representatives of local NGOs, Community based organizations (CBOs), and church groups, are the catalysts that mobilize neighborhood committees. They have assisted poor neighborhoods in gaining recognition from the ministry of education for their community schools, approval for their syllabus, and training for their volunteer teachers.

community consensus around the agency's goals.

- Outside support seeks to build capacity of communities rather than to deliver services. The catalyst's role is to sensitize, mobilize, and build capacity. Outsiders can catalyze the process in a somewhat systematic fashion, but neither they nor funding bodies can dictate the specific actions a community eventually undertakes without undermining ownership and, therefore, sustainability.
- The process should be allowed to unfold according to the community's internally defined rhythm. Emphasis is on a process that is iterative and incremental. Taking sufficient time and the timing of outside support are 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.

Related Issues

To mitigate the effects of HIV/AIDS, projects must also address (1) scale and sustainability, (2) the link between care and prevention, and (3) integration within and among programs.

Scale and sustainability

In the countries most affected by HIV/AIDS, the consequences are far too great, varied, and interrelated for any single organization, government, international body, or NGO to address unilaterally. Coordination and collaboration are essential among all relevant participants. HIV/AIDS is a development issue, not just a health issue. Cost-effective, sustainable interventions must be expanded to produce sustainable results on the same scale as the problems.

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."

Linking care and prevention

The care and support of people living with AIDS should be linked closely with efforts to mitigate economic and psychosocial consequences. The possible links between care and prevention

The Families, Orphans, and Children Under Stress (FOCUS) Program in Mutare, Zimbabwe, has mobilized volunteers to visit orphans regularly, monitor the orphans' situation, respond with community resources, distribute small amounts of externally provided material support, and refer urgent problems to government authorities. Approximately 4,000 orphans benefit from the program, which costs about U.S.\$3 per year per child visited. The breakdown of the program's 1998 budget of U.S.\$13,800 is as follows: 44 percent for material assistance, 7 percent for volunteer allowances and uniforms, 5 percent for volunteer training and meetings,

and 44 percent for salaries of the Coordinator and Assistant Coordinator and for administrative costs. Efforts are under way to increase program efficiency by integrating the orphan-visiting program with home-based care and HIV/AIDS prevention activities.

activities deserve greater attention than they have received. Programs targeting prevention often operate in isolation from those providing care for persons living with AIDS, orphans, and others made vulnerable by the epidemic. Efforts to link care and prevention could be important in reducing the spread of HIV. Poverty generates a sense of powerlessness and fatalism. The feeling that the events that affect people are beyond control undermines commitment among the poor to heed prevention messages. 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 the risk of HIV infection.

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 at which HIV infection spreads. 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."

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

Because families and communities form the "front line" of response to the effects of the HIV/AIDS pandemic, programs must be designed to make sense within that context. 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. More integration within and among programs can improve the interventions.

CHALLENGES

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

Ownership at the 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 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. Among the incentives that volunteers receive are monthly bus fares to meetings; a T-shirt, skirt, training shoes, and scarf once per year; and an annual Christmas bonus of U.S.\$10. Volunteers receive initial and monthly training. Some volunteers make exchange visits to other programs. Volunteers who care for orphans in their own homes may receive small amounts of material support (an average of U.S.\$11 per year).

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 the activities. Another component 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 the need for income-generating activities, many community groups start businesses. These communal enterprises are notoriously risky endeavors that generally do not generate significant profits and that 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 take community members away from the very activities the business is meant to finance. Some communities have had success by putting such a business in the hands of a qualified manager.

Systematic Mobilization

The structure of a community mobilization program in Malawi is based on participation at three levels: the district, the health catchment area, and the village. Initially, the NGO acting as the catalyst mobilized effective action at the health catchment and village levels. When the program began to work in another area, it started at the district level, thereby intending to start a “cascade” effect (i.e., district-level participants mobilize health catchment areas, which in turn mobilize 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. Staff are reassessing how to scale up.

Strengthening Household Economic Resources

HIV/AIDS is having a profound economic effect at the family and community levels. Communities have been mobilized to provide assistance to their most destitute members. But how can these efforts be sustained, 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 is state-of-the-art microfinance programs. Such programs are extremely challenging to implement, however. To design and manage a community mobilization initiative and to deliver microfinance services require expertise in and a focus on those activities. The best course for a group with expertise in community mobilization is to work in partnership with a specialized microfinance organization.

Some microcredit practitioners have taken the position that communities seriously affected by AIDS are not likely to be acceptable credit risks. Experience suggests otherwise. In Uganda, Uganda Women’s Finance Trust and Foundation for International Community Assistance (FINCA’s) village banking program started in 1992 with United States Agency for International Development (USAID) and Displaced Children and Orphans fund (DCOF) funds. The program has worked well in communities seriously affected by HIV/AIDS. In fact, the 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 that have been seriously affected by AIDS, yet the program there 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 provoke community participation in their projects. However, it is unclear whether external grants to communities are an effective way to support responses to HIV/AIDS-related problems. Although external funding may help stimulate efforts, it runs the risk of compromising those efforts by diluting community ownership. External funding 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. Another risk is that a community can exhaust all its own resources. When that happens, the community can become demoralized and overwhelmed. Under those circumstances, a modest and carefully timed injection of external resources would make a significant positive difference. To avoid creating dependency or despondency requires outside organizations to exercise a skillful and thoughtful program approach and regular communication with people in the community.

Village-Driven Needs

Many agencies specialize in a particular technical area. Therefore, community- and village-level activities often end up reflecting an NGO's specialization rather than the beneficiary's needs. People living with or affected by HIV/AIDS do not segment their lives according to neatly defined technical sectors, however. Those people must identify issues and set priorities.

Monitoring and Evaluation

Monitoring and evaluation must be sensitive to community ownership and to the need for information, yet they must comply with donor requirements. In Malawi, one community had successfully identified indicators that were compatible with donor requirements. The NGO began presenting these indicators as a "package" to other villages, which consequently felt that the package had been imposed on them and that they had had no voice in the process. Communities ceased to gather information and behaved as though the information were "owned" by the NGO.

GUIDELINES FOR CATALYSTS AND DONORS

Successful community mobilization to mitigate the effects of HIV/AIDS requires catalysts and donors to do the following: (1) collaborate in cost-effective strategies, (2) build an enabling environment, (3) work through and with organizations that already exist in communities, (4) promote state-of-the-art participatory development techniques, (5) create design and methodological innovations to scale up project outreach, and (6) promote a two-pronged technical assistance approach.

Because the problems caused by HIV/AIDS are too great for any government, donor, or organization to effectively address by acting alone, donors and other organizations that intervene must define common strategies and collaborate closely—just as individuals are doing on the front line in affected communities. They must also give serious attention to cost-effective strategies and interventions, including those fundamental strategies that will build 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

One of the obligations of catalysts and donors is to find ways to make it easier for vulnerable families and communities to cope. Included in that obligation are the following activities: (1) increasing the awareness and commitment of community leaders and the public concerning children who are especially vulnerable; (2) establishing laws and policies that protect children and widows; (3) reducing the stigma and discrimination associated with HIV/AIDS; (4) monitoring the epidemic's consequences and the effectiveness of interventions; and (5) increasing the awareness, effectiveness, and coordination among key government bodies, international organizations, donors, NGOs, and CBOs. In addition, governments have a critical role to play in protecting and placing children who are abused or neglected, establishing and monitoring compliance with policies, and delivering such essential services as health care, education, and access to clean water.

There are advantages to working through organizations or structures that are already active in a community. Costs of such programs tend to be lower, and the programs are more likely to be sustained. Churches and other religious bodies, health services, neighborhood health committees, schools, civic organizations, women's associations, and cooperatives that are already established may be ideal candidates to deliver HIV/AIDS-mitigating services.

Proficiency or effectiveness in participatory techniques that spark genuine community ownership cannot be acquired by reading a book or by a onetime training workshop. Although these activities 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. The process takes patience and commitment, but once a foundation of genuine community ownership has been established, progress is often very rapid. In addition to developing their own skills, catalysts must also strengthen mobilization and participation skills at the community level.

For community mobilization programs to scale up, there must be effective links between communities and external structures and resources. Catalysts (whether NGOs or extension agents) must promote genuine commitment to the participation from the community level 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. Also, periodic retreats that allow staff members to review and analyze their progress will allow them to better identify their support needs and plan future strategies.

Strengthening household economic resources and community safety nets are two critical aspects of the effort to mitigate the effects of HIV/AIDS. Because 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. Joint planning would focus on (1) the desired effect of microcredit, (2) monitoring and evaluating the actual affect, and (3) packaging loan products to reach target clients.

REFERENCES

Williamson, John, and Jill Donahue. "Community Mobilization to Address the Impacts of AIDS: A Review of the COPE II Program in Malawi, January 17–30, 1998." Report prepared by the Displaced Children and Orphans Fund and War Victims Fund Project for United States Agency for International Development, June 1998.

Hunter, Susan, and John Williamson. "Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS." Report prepared by the Health Technical Services Project for the United States Agency for International Development, 1998.