

**Summary of
Expanding and Strengthening
Community Action**

A Study of Ways to
Scale Up Community Mobilization
Interventions to Mitigate the Effect of
HIV/AIDS on Children and Families

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HIV/AIDS has had a debilitating effect on many nations, communities, and families. Some parts of the world have been particularly hard hit, with sub-Saharan Africa bearing the brunt of the epidemic. Of the approximately 50 million HIV infections in the world, more than 72 percent are in sub-Saharan Africa. In addition, 84 percent of AIDS deaths are from Africa; of the 13.2 million children who have had mothers or both parents die because of AIDS, 95 percent are in Africa. It is predicted that the numbers of orphans will continue to rise, reaching 40 million by 2010 (UNAIDS 2000). Even if rates of new infections leveled off, mortality rates would not plateau until around 2020 because of the unusually long HIV incubation period. Hence, the proportion of orphans will remain unusually high for several decades, at least until 2030. The United Nations Children's Fund (UNICEF) estimates that Botswana, Malawi, Zambia, and Zimbabwe will have the highest proportion of orphans through this period (Levine and Foster 2000).

Clearly, the major—and indeed most immediate—challenge is scaling up the responses to match the magnitude and duration of the HIV/AIDS pandemic. Families and communities, absorbing and providing for orphans as best they can, are the first line of response. However, the unprecedented scale of the problem has weakened the ability of families and communities to respond as they have in the past. Extended families must be strengthened to absorb the growing numbers of orphans.

The specific goal of this study was to develop a set of recommendations on how to scale up effective, sustainable community mobilization and capacity-building interventions to mitigate the effects of AIDS on children and families in the countries most seriously affected by the pandemic. The study objectives in support of that goal explored and examined the following issues:

- Coping strategies in different communities
- Stakeholder roles, responsibilities, and relationships at household and community, district, and national and international levels

- Existing or potential plans for scaling up current orphan protection and care initiatives
- Existing and potential direct support to communities affected by and responding to the effects of AIDS
- Existence of an enabling environment
- Establishment and support for participatory program monitoring
- Mechanisms for establishing centers of learning

The study was carried out by a three-person team over a four-week period in July and August 2000. In Malawi, interviews and discussions were held in and around Lilongwe (the administrative capital), Blantyre (the commercial capital), Mangochi, Nkhota Kota, and Dedza. In Zimbabwe, meetings were held in and around Harare, Mutare, and Zvishavane.

The study team envisaged change in two main areas: (1) programmatic methods and approaches, with analysis of strengths and limitations, for systematically mobilizing and strengthening the capacities of communities to respond to the needs of their most vulnerable children and households and (2) global, regional, and national efforts to develop and implement effective strategies to systematically mobilize AIDS-affected communities to benefit the most vulnerable children and households.

For AIDS programs to flourish, there must be an enabling environment. Political leadership is crucial and can galvanize support from government groups, religious organizations, NGOs, and international donors. Through laws and policies, governments have a responsibility to establish a framework that supports the coping capacities of communities, families, and individuals. Governments can play a role at the national, district, subdistrict, and village levels. With its leadership, power, structure, and resources, the government is uniquely positioned to lead national responses to the problem of orphans and vulnerable children.

In view of the government's undisputed position in influencing an enabling environment, its pivotal role must be recognized and its function facilitated. Those conditions can be met through the adoption of strategies that use existing government structures and resources, involve consultations and partnerships with government departments, engage political leaders in community initiatives, and apply issue-specific advocacy and monitoring of the problem.

Three community mobilization programs that have led to expanding programs for orphans and vulnerable children have been widely recognized. The COPE program, operated by Save the Children (US), mobilized communities at area and village levels in Malawi to respond to the needs of orphans and other vulnerable children. COPE modified its initial high-cost-per-beneficiary approach by reducing staff size and shifting its focus from addressing problems to

mobilizing and building the capacities of communities. A structure of committees was established at the district, community, and village levels involving a cross section of the population.

In the second phase, through the committee structure, the COPE program expanded into 30 catchment areas of six districts. A total of 248,967 people benefited directly or indirectly from the program at an average annual cost of US\$317,000 (DCOF 1999).

The Families, Orphans and Children Under Stress (FOCUS) program in Zimbabwe emphasized identification and monitoring of vulnerable children through visiting households regularly, sponsoring community ownership, keeping children in school, establishing income-generating activities, and training and motivating volunteers. The program was established and maintained in close liaison with community leaders.

Respected and credible people of good standing were nominated by the community and church leaders to be volunteers in the pilot FOCUS program. Volunteers were initially trained by FACT staff, and ongoing training, supervision, and monitoring were provided by the program coordinator. Volunteers identify unmet basic needs of the households and provide essential material support. Visits also provide emotional and spiritual support. Volunteers are also involved in advocacy and awareness raising of orphan issues. The pilot program has been widely replicated because it has enjoyed strong community ownership, kept costs low, and required minimal external technical support.

The Bethany Project is a program for orphans and vulnerable children in Zimbabwe. The program involved community members from the outset. It started in two wards with 35 volunteers. Volunteers who were recruited from local churches provided regular visits to vulnerable children living nearby. The Bethany Project works well with other partners in the district, including government structures, local NGOs, and members of the Child Welfare Forum. A strong relationship with the Department of Social Welfare has been beneficial to the project.

The expansion of the Bethany Project led to several problems. The two original sites had come to rely heavily on the NGO for material support and assistance, and the project's expansion led to a reduction in the frequency of support visits and amount of material resources to the original sites. Currently 8,004 children receive regular visits and material support, and the organization's budget for 2000 was around US\$20,000.

The three programs described above exemplify two different approaches to community mobilization. The Bethany Project and the FOCUS program have the greatest similarities of program design and strategy. Both programs use community mobilization of churches to establish groups of volunteers who are committed to regular household visits and other orphan support activities. The COPE program mobilizes community and village AIDS committees to engage community members in a wide range of support activities. In the COPE program, the target is not specifically orphans.

In the last decade, the response of communities in sub-Saharan Africa to the effect of AIDS on their children has been nothing short of astounding. Hundreds, if not thousands, of community initiatives are organizing responses and molding themselves into coordinated child support programs. The initiatives involve decision making by committees; local leadership; consensus-based activities; and local mobilization of finances, materials, and volunteers. Activities include foster care for children by extended families, nutrition gardens, material support from neighbors, spiritual support and counseling, home visits, income-generating projects, raising funds for school fees, referral services, getting children back to school, advocacy for children's issues, and community schools. Mobilization of the community from within leads to expansion of the volunteer and resource bases and to the scaling out of activities. Many community initiatives that support programs for orphans and vulnerable children have built on such existing community activities as the following:

- Religious institutions that support persons in need
- Traditional and income-generating activities (IGAs)
- Existing home care programs
- Support groups for persons living with AIDS

Scaling out increases the number of families, communities, and organizations being reached by effective services. It may involve adding new or more comprehensive services, expanding geographic coverage of services, and building the capacity of organizations to enable them to meet increased demand. Expansion occurs because of increased need at the community level, for strategic reasons, and in response to humanitarian, macroeconomic, and geopolitical considerations.

Program expansion may be initiated at different levels. Program implementers such as CBOs and NGOs may expand their programs by increasing coverage, expanding their area of operation, or promoting replication by other implementers. Program facilitators such as NGOs and government departments may encourage program expansion by new or existing partners, or they may encourage other organizations to copy child support programs through the provision of training, capacity building, and exchange opportunities for visiting organizations.

Intermediary organizations like COPE, FOCUS, and the Bethany Project play a strategic role in facilitating the development and expansion of the HIV/AIDS programs of CBOs and NGOs. Intermediary organizations have much greater potential to have an effect on the scale of the response than implementing organizations. Critical to the success of the mobilization process are consistent and sustained awareness raising, motivated volunteers, participatory methodologies, partnerships between NGOs and community groups, appropriate training, capacity building, and documentation and dissemination of experiences.

A number of factors facilitate the scaling out of community mobilization interventions to mitigate the effect of HIV/AIDS on children and families. Leaders are essential, and respected leaders are especially effective. Faith-based organizations have credible leaders as well as existing structures and effective channels of communication. To expand programming, organizations should identify and work through existing structures as much as possible. Individuals as well as NGOs are instrumental in encouraging existing community initiatives to develop more systematic child support programs. Coalitions that involve people from a broad range of interests maximize the use of local human resources. Finally, it is necessary to elicit long-term commitments as HIV/AIDS continues to erode the capacity of communities to care for persons affected by the disease.

Scaling out can lead to problems, however. Staff members may be unable to maintain monthly site visits if the number of program sites increases. Also, staff members may be expected to change their orientation from implementation of support activities to facilitation of responses by community groups. Volunteers may feel overburdened and overwhelmed by the expansion of community programs. Program expansion by implementing and facilitating organizations may lead to a reduction of material resources for the initial community groups. Increased community ownership may mean that facilitating organizations receive less accurate monitoring data, too. Community advocates fear that outside organizations may not understand the nature of community initiatives. The lack of organizational capacity is sometimes a barrier to scaling out. Finally, funding or material assistance that is channeled inappropriately can undermine local efforts by affecting community solidarity and motivations.

One of the fundamental questions in the area of expanding programs to support vulnerable children concerns whether the strategy should or should not be driven predominantly as a top-down scaling-up approach. International and national agency strategists need to realize that the problem of children affected by AIDS is not primarily their own. The problem belongs to affected communities. When viewed from that perspective, the primary responsibilities of outside agencies are to strengthen the existing programs, activities, and endeavors that have been initiated by communities whose children are affected by AIDS. Thousands of communities in Africa have developed ingenious programs to cope with the increasing numbers of vulnerable children within their midst. Local efforts typically do not match the level of need among orphans and other vulnerable children—hence the need for systematic scaling up, scaling out, and capacity building.

External change agents must recognize that families and communities are the first line of response to persons affected by HIV/AIDS. Those outside agents must then try to understand the community's coping strategy. For community mobilization and capacity building to be efficient and effective, it is important that all participants are identified and that their roles, responsibilities, and relationships are clearly recognized and articulated. Experience has demonstrated that multisectoral, collaborative, and coordinated responses are essential because the AIDS problem is so complex. Outside organizations can provide much-needed technical support as well as small

amounts of targeted material support for community efforts. Top-down efforts to strengthen community action must not undermine community initiatives but support flexible programming approaches. An expanded response is built through partnerships. That thinking should also inform data collection. First and foremost, monitoring data must serve the needs of the community. Political commitment and support as well as a policy and legal environment that is supportive of children's issues are important to the promotion of community-based and community-managed responses. Finally, catalyzing organizations and active communities can serve as learning centers where visitors from other communities can learn about the responses and dynamics of community action, replicating and adapting program approaches for their initiatives.

Families and communities affected by HIV/AIDS are carrying and will continue to carry the primary responsibility of protecting and caring for orphans and other especially vulnerable children. They are service providers, and external change agents must recognize that. Such an understanding will allow for appropriate, tailored support to communities and a more informed appreciation of the complexity of the AIDS problem at a global level.