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10

Finding a Way Forward

Reducing the Impacts of HIV/AIDS on Vulnerable Children and Families

John Williamson

The number of children and families made vulnerable by HIV/AIDS is massive and will remain so for decades. As the previous chapters have shown, the pandemic is causing unprecedented child and family welfare problems, and the collective response in every seriously affected country falls far short of what is needed. What affected children and families require and what their own countries and the international community owe them is a combination of efforts, large and small, that collectively match the scale and duration of the impacts of AIDS. However, only a small percentage of children and families affected by HIV/AIDS are currently benefiting significantly from assistance from outside their own extended family (USAID, UNAIDS, WHO, UNICEF, and The Policy Project 2004:27). While many effective programs are in operation, there remains a huge gap between the results of these initiatives and what needs to be done. This chapter recommends strategies and interventions that, taken together, would begin to close the gap between what is being done and what must be done.

THE ELEMENTS OF AN ADEQUATE AND EFFECTIVE RESPONSE

By itself, no single intervention will make a sufficient impact on the full range of economic and psychosocial problems HIV/AIDS is causing among children and families, because the problems are too many and too varied. What is needed is a planned and coordinated set of policy, social-mobilization, and programmatic interventions by public sector and civil society actors. Achieving this goal requires a strategic response from leaders that only recently has been seen in a few countries.

If governments and other key stakeholders are to mobilize and guide strategic responses, leaders at every level of government must understand the type of collaborative responses needed and use their policy and public leadership capacities to support sustained, multisectoral commitment to the task. Uganda, Thailand, and Senegal have shown that

open, committed leadership in vigorous prevention efforts can make a difference in an HIV/AIDS epidemic. UNICEF/ bilateral donors such as USAID (U.S. Agency for International Development), and nongovernmental organizations (NGOs) are playing critical supportive roles, particularly in sub-Saharan Africa, in stimulating and helping to guide national policy development and planning regarding orphans and vulnerable children.

Massive, sustained action by national and international actors is essential to build an effective response to children made vulnerable by AIDS, and the primary emphasis must be to strengthen family and community capacities for protection and care. The vast majority of children orphaned by AIDS are living with a surviving parent or within their extended family, but HIV/AIDS and poverty continually erode caretakers' ability to meet even the basic needs of these children. As shown in Chapter 1, on the scale that is needed there are no viable alternatives to family and community care for orphans and vulnerable children. Unless the coping capacities of families and communities seriously affected by AIDS are reinforced, the number of children slipping through these primary social safety nets will overwhelm any feasible set of alternative-care programs.

Building family and community capacities, however, is not enough. Through school and other opportunities for learning and action, children must be prepared to meet their own needs. Governments must provide essential services and ensure protection and care for children outside family care - on the street, in child-headed households, or in residential care. Broad social mobilization is also necessary to counter stigma and discrimination and promote support for children and households in greatest need.

In 2001 the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS passed the Declaration of Commitment on HIV/AIDS (United Nations 2001), which includes specific goals regarding orphans and vulnerable children (see Figure 10.1). These goals have spurred some governments to develop national policies and action plans. Their commitments and plans must be translated into adequate support to those living on the front line.

Through a series of regional workshops in Africa organized by UNICEF, USAID, and other organizations, a consensus has emerged in favor of five steps each country must take to achieve the UNGASS goals for the needs and rights of orphans and vulnerable children:

1. Carry out a collaborative national situation analysis concerning orphans and vulnerable children.
2. Develop a national plan of action.
3. Address policy issues.
4. Establish mechanisms for information exchange and collaboration.
5. Monitor and evaluate interventions.

We, the heads of state and governments, declare our commitment to...

65. By 2003, develop and by 2005 implement national policies and strategies to: build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counseling and psycho-social support; ensuring their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children; to protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance;

66. Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of destigmatization of children orphaned and made vulnerable by HIV/AIDS;

67. Urge the international community, particularly donor countries, civil society, as well as the private sector to complement effectively national programmes to support programmes for children orphaned or made vulnerable by HIV/AIDS in affected regions, in countries at high risk and to direct special assistance to sub-Saharan Africa.

Source: United Nations 2001.

FIGURE 10.1. Goals Concerning Orphans and Vulnerable Children Included in the United Nations General Assembly Special Session on HIV/AIDS

ANALYZING THE SITUATION

Building an adequate response requires careful consideration of the factors that drive an HIV/AIDS epidemic and its social, political, and economic consequences. It is necessary to recognize the problems at the individual level - how parents, children, and orphans' guardians are affected and struggle daily to cope. But this perspective, by itself, is inadequate to guide the scaling up of responses to these problems. As stressed in the Introduction, it is also essential to take into account the magnitude and duration of the HIV/AIDS pandemic and its collective impacts. The individual and aggregate consequences of HIV/AIDS play out differently in every country. Thus, situation analysis and ongoing monitoring are essential to planning and implementing effective interventions.

Situation analysis involves gathering and analyzing quantitative and qualitative data about the social, economic, cultural, religious, historical, and demographic dimensions, as well as information on resources, capacities, and problems and the dynamic interrelationships. It also includes gathering information about a country's HIV/AIDS epidemic, including its consequences, household and community coping responses, and relevant policies and programs. Once the information has been gathered and analyzed and geographic and programmatic priorities have been identified, specific actions can be recommended. Situation analysis provides a

basis for making difficult choices about how and where to direct available resources to benefit the most seriously affected children and families. A situation analysis is also an important means of building consensus among key stakeholders. Collaboration to mitigate the impacts of HIV/AIDS becomes essential as a country's epidemic spreads. Conducting a situation analysis as a broadly inclusive, participatory process is a way to bring together key agencies and organizations - those already engaged and those who will need to be. Participants develop a shared understanding of the situation and reach consensus on the best way forward and the next steps. A participatory situation analysis should enable the organizations involved to reach consensus on priority issues and generate information on the current and future magnitude of orphaning and other impacts of HIV/AIDS on children and families. For program heads and policymakers, a situation analysis should provide clear answers to the question. Why should I care about these issues?

As has been seen in Zambia, Namibia, Uganda, and other countries, broad participation is important. Participants can include relevant government ministries or departments, international organizations, donors, NGOs and their coordinating bodies, associations of people living with HIV/AIDS/ religious bodies and programs, women's associations, members of seriously affected communities, university departments, civic organizations, the business community, and other concerned groups. Actively involving stakeholders in a situation analysis increases the likelihood of their feeling ownership of the findings and being committed to implementing its recommendations. Inclusive participation means the process will take longer than one contracted out for implementation by a technical group, but the investment in time can make the difference between a report that occupies shelf space and a process that generates action.

A situation analysis should identify the geographic areas where families and communities are having the most difficulty protecting and providing for the most vulnerable children, and thus where action is most urgently needed. Identifying geographic priorities requires consideration of such information as census or survey data on orphaning and adult mortality; the pattern of spread of an epidemic; its impacts on different farming systems and other economic activities; vulnerability indicators regarding health, nutrition, education, and other factors; and the geographic reach and effectiveness of current services. Geographic priorities for action should not be based, however, only on statistical information. They also require validation through active consultation with people living and working in HIV/AIDS-affected communities.

The process should produce specific recommendations for action. Simply making a wish list will not help, though. Participants must identify what needs to be done, by whom, within a specified time frame. Considering all their recommendations, participants should organize, integrate, and present them in terms of sequence and strategic priorities. A participatory

situation analysis is a springboard to generate decision making, planning, and action.

A situation analysis provides an overview of the impacts of HIV/AIDS on children, responses to the problems, and priorities for action, but because conditions will continue to evolve, ongoing monitoring is also necessary to help guide and adjust interventions over time. A system to monitor the impacts of AIDS on children and families should be one of the results of a situation analysis. The process will have identified sources of information that can be tapped periodically for ongoing monitoring of changing circumstances. One of its recommendations should identify a body to be responsible for compiling, analyzing, and disseminating relevant information to track trends (Williamson, Cox, and Johnston 2004).

A STRATEGIC FRAMEWORK

Countries with advanced epidemics have recognized that HIV/AIDS is not just a health issue but a major development issue as well. Agriculture, education, health, social welfare, community development, and business all are seriously affected, and a multisectoral, strategically linked set of responses is necessary. The beginnings of such a coordinated response are emerging in some of the worst-affected countries.

Government policy and public leadership can make a difference in the course of an HIV/AIDS epidemic. NGOs are developing effective interventions. Faith-based groups and networks are also emerging as structures with great collective potential for responding to HIV/AIDS. Their efforts are most likely to make a difference if all of these actors listen to and strengthen the capacities of families and communities who are the first line of response.

An effective response to the impacts of HIV/AIDS requires the active, ongoing collaboration of actors across all sectors. In addition to estimates and projections on orphaning. *Children on the Brink 2004* (USAID, UNICEF, and UNAIDS 2004: 22-4) presents the following five strategies to guide development of an effective national response to the impacts of HIV/AIDS on children and families. (For an earlier version of these strategies, see USAID, UNICEF, and UNAIDS 2002:13-14).

1. Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial, and other support.
2. Mobilize and support community-based responses to provide both immediate and long-term support to vulnerable households.
3. Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration, and others.¹

¹ *Children on the Brink 2002* (USAID, UNICEF, and UNAIDS 2002) and its two previous versions referred to building children's capacities to meet their own needs. Comments

4. Ensure that governments protect the most vulnerable children through improved policy and legislation and by channeling resources to communities.
5. Raise awareness at all levels through advocacy and social mobilization to create a supportive environment for children affected by HIV/AIDS.

These five strategies provide a framework for each country to shape its own comprehensive response. An uncoordinated collection of individual programs is inadequate: The programs must fit together into a coherent whole shaped by a national policy and plan of action. But national policies and plans will not be effective if they are simply imposed from the top. To ensure that policies and plans are grounded in reality and have legitimacy in the eyes of those expected to implement them, they must be developed with the participation of the community groups on the front line and the agencies that will be involved.

Governments have a responsibility, through laws, policies, and action, to support the coping capacities of individuals and families and provide them basic protection. Fulfilling these responsibilities requires particular attention to the situation of children and women; key elements of a framework to protect them include laws and effective structures for their implementation, such as provisions for:

- protection of children against abuse, neglect, and sexual contact with adults,
- elimination of barriers to school enrollment and completion,
- prohibition of discrimination in health care, schools, employment, or other areas based on actual or presumed HIV status,
- protection of the inheritance rights of orphans and widows,
- enactment and enforcement of laws ensuring women the right to own property,
- prohibition of harmful child labor, and
- protection and care for children without adequate family care, including children of the street, those in residential care, and child-headed households.

PROGRAMMATIC INTERVENTIONS

If the needs and rights of children made vulnerable by AIDS are to be fulfilled, a set of interventions appropriate to each country must be scaled up through increased coverage, scaled out through replication, and sustained for decades. When agencies consider possible programmatic interventions,

made during the review process of *The Framework*/or the *Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* indicated that this concept was not clear, and the current wording was substituted. This change clarifies part of the strategy, but unfortunately omits what many advocates feel is the essential element of children's active participation. The editors recommend that subsequent versions of *Children on the Brink* and *The Framework* clearly affirm the importance of children's participation.

they need to assess and compare the respective potential of alternative approaches for improving the capacities of families, communities, and vulnerable children to meet their own needs. In a country with an advanced HIV/AIDS epidemic, the most effective interventions are those that:

- fulfill children's basic needs and rights,
- are directed to the most vulnerable geographic areas, communities, and population groups,
- are targeted, in turn, by each community to its most vulnerable children and households,
- can be sustained for decades or generate ongoing improvements in coping,
- have an affordable cost per beneficiary,
- are widely replicable, and
- mesh together into an adequate collective set of responses.

Recognizing the need to provide guidance regarding programs for children affected by HIV/AIDS, UNICEF, USAID/ and UNAIDS (the Joint United Nations Programme on HIV/AIDS) initiated a consultative process to forge international consensus on principles to guide programming. The process began at the 13th International AIDS Conference in Durban, South Africa, in July 2000 and incorporated feedback from subsequent regional meetings involving governments, NGOs, international organizations, the private sector, community organizations, and young people. It culminated with the formation of the Global Partners Forum in October 2003. The synthesis of this process, *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, was issued in July 2004. It can be used to guide collaborative action at each level, from grassroots to national and international efforts. The Framework presents a version of the original five development strategies and includes program guidance on the following key points (27-30):

- Focus on the most vulnerable children and communities, not only children orphaned by AIDS.
- Define community-specific problems and vulnerabilities at the outset and pursue locally determined intervention strategies.
- Involve children and young people as active participants in the response.
- Give particular attention to the roles of boys and girls, men and women.
- Address gender discrimination.
- Strengthen partnerships and mobilize collaborative action.
- Link HIV/AIDS prevention activities, care, and support for people living with HIV/AIDS, and support for vulnerable children.

- Use external support to strengthen community initiative and motivation.

KEY INTERVENTIONS

A mix of interventions is needed to build an adequate, collective response to orphans and vulnerable children. This section gives an overview of seven categories for each country to consider as it develops its set of responses: education, community mobilization and capacity building, microeconomic strengthening at the household level, other development interventions, direct services, support grants, activities to promote the psychosocial well-being of children affected by HIV/AIDS/ and a very broad set of interventions that includes HIV prevention and treatment and the care of those living with HIV/AIDS.

Education

Education is fundamental to the well-being and development of all children and is recognized as a human right by the United Nations Convention on the Rights of the Child (CRC) (United Nations 1989). Making primary education free and compulsory for all children is among the responsibilities undertaken by governments that have ratified the CRC. The reality, however, is that in developing countries there are educational costs, and typically the poorest children have difficulty attending school. The vulnerabilities caused by AIDS exacerbate attendance problems.

Paying school expenses can be a prohibitive financial burden for families affected by AIDS. Girls, on whom future family and community well-being substantially depend, are often forced to drop out before boys. From the national to the community level there have been a variety of responses to help orphans and other vulnerable children stay in school, but there are no easy answers to the resource deficits HIV/AIDS is causing (Hepburn 2001). Providing scholarships is a direct and efficient solution, but the expense makes it difficult to sustain as an escalating number of children are pushed out of school. Some ministries of education have waived school fees for orphans, which helps, but the resulting deficits in ministry and school budgets have to be made up from other sources.

Some organizations have provided supplies and equipment and constructed classrooms for schools prepared to accept orphans. Some communities have started their own basic schools to provide education for children unable to afford regular schools. The schools may be less expensive per pupil than government schools, but communities face significant challenges to support them indefinitely (Nampanya-Serpell 1999; Sikwibele, Mweetwa, and Williamson 2001). Countries such as Malawi, Uganda, and

Kenya that have eliminated all fees for primary school have seen dramatic increases in enrollment.

Some orphans are not in school simply because their guardians do not send them. Community groups concerned with orphans and vulnerable children in Zambia and Malawi have helped some students return to school by persuading guardians that these children need an education. Appeals by local religious groups, emphasis on traditional values and responsibilities, parenting skills classes, and sensitization to children's rights help motivate some care providers to send children to school.

Measures to improve household economic capacity, particularly where the participants are women, can be one of the most important and sustainable ways to address problems of educational access. Evaluations of micro-finance programs involving women (for example, Adelski et al. 2001; Alien 2002; Alien, Koegler, and Rushawa 2002; Tumushabe 1999; Wright et al. 1999) have found that educational expenses are one of the primary uses of participants' income. Chapter 3 addresses these and other education issues.

Community Mobilization and Capacity Building

Community mobilization is a process through which a community (on its own or with an outside catalyst) identifies and takes action on its shared concerns. Capacity building involves strengthening or developing skills, methods, and organizational functioning. It may include linking communities with outside resources (training and information or material, financial, or technical support) or providing limited resources to the community. External resources must follow mobilization and action initiated by the community, however, not lead it. Effective mobilization is based on community ownership of a problem and a sense of responsibility to address it. Community mobilization is not a matter of persuading people to take action by giving them resources, nor to work as volunteers in an agency's program.

Communities become mobilized when residents collectively define strongly felt, shared concerns and identify how they can address these concerns themselves (Donahue and Williamson 1999). As a large number of communities have shown, people at the grassroots level are not only concerned about the growing number of orphans and vulnerable children, they are also prepared to respond to their needs using local resources. Some groups eventually secure additional funding or material support from external sources.

While many community groups have addressed the needs of orphans on their own initiative, it would be unrealistic to expect that most communities will eventually do so. Spontaneous grassroots efforts are scattered and their collective coverage is limited. The programmatic challenge is to develop ways to systematically assist communities to mobilize their responses and

The Families, Orphans, and Children under Stress (FOCUS) Program in Mutare, Zimbabwe, has mobilized volunteers to visit orphans regularly, monitor their situation, respond as appropriately as possible with community resources, distribute small amounts of externally provided material support, and refer urgent problems to government authorities. Some nine thousand needy children benefit from the program, and the cost per household visited was less than US\$10 per year in 1998 and lower the next year. Its 1998 budget of US\$13,800 broke down as follows: 44 percent to material assistance, 7 percent to volunteer allowances and uniforms, 5 percent to volunteer training and meetings, and 44 percent to salaries of the coordinator and assistant coordinator and administrative costs. Program efficiency was subsequently increased by integrating visiting orphans with home-based care and HIV/AIDS prevention activities. The FOCUS Program is implemented by Family AIDS Caring Trust (FACT).

FIGURE 10.2. FOCUS: A Volunteer Program in Zimbabwe

help them sustain their efforts. Programs such as those described in Figures 10.2 and 10.3 have shown that this is possible, with limited amounts of support.

Communities' strongly felt concerns for their children are the driving and potentially sustaining force behind their initiatives. Concerns are not created by the community mobilization process; rather, the coming together of mobilized communities, both rural and urban, stimulates a shift in perception from seeing the needs of orphans and, especially, vulnerable children as being the responsibility of individual households to recognizing that children's needs are a shared community responsibility that can be addressed more effectively through cooperative efforts. Because the motivation to participate comes from shared personal concerns, communities must define for themselves which children and which threats to their current and future well-being concern them most. Consequently, an outside agency cannot predetermine the specific activities or outputs that the process will generate, or even the specific issues that will be addressed. These are decisions community members must make for themselves. Mobilizing a community or building its capacity does not necessarily mean helping it to develop a new organizational structure. It may involve enabling an existing community committee, school, religious group, women's association, or other body to broaden or strengthen its action for vulnerable children and households.

The specific kinds of capacity building needed after an initial mobilization process depend and build on a community's existing capacities, opportunities, resources, and commitment to its most vulnerable children. Capacity building may include training in writing proposals, developing and managing programs, mobilizing local resources, fundraising, or training in child development, health care, nutrition, and children's rights.

Zambia's Strengthening Community Partnerships for the Empowerment of Orphans and Vulnerable Children (SCOPE-OVC) was designed to mitigate the impact of HIV/AIDS on orphans and vulnerable children through mobilizing, strengthening, and scaling up community led responses aimed at benefiting orphans and vulnerable children. The project has organized district and community committees in twelve of the country's seventy-three districts. Collectively, these committees reached over 137,000 orphans and vulnerable children in 2002, over 26 percent of the estimated total number in these districts. In ethnically mixed urban communities and rural areas, they have helped residents to respond to children in need. Many community committees have started community schools for children too poor to attend government schools. Other community initiatives include intervening to protect abused children and organizing group income-generating projects. The district committees also provide a forum for information exchange and coordination among government, NGO, church, and business members. The SCOPE-OVC project is being implemented by CARE Zambia supported by Family Health International with funding from USAID.

Other capacity-building efforts include strengthening district and community partners to address the interrelated issues of children's psychosocial needs and household economic strengthening through training in community and resource mobilization, strategic and action planning, monitoring and evaluation, business development and microfinance services, and psychosocial support.

To supplement local mobilization efforts, the project has a small grants component aimed at helping communities and organizations scale up the support they are providing.

FIGURE 10.3. Mobilizing Communities in Zambia: SCOPE-OVC

It is an ongoing process that involves helping communities (1) identify and use their own capacities and local resources, (2) develop skills in assessment, decision making, planning, monitoring, and evaluation, and (3) link with external resources. Chapter 1 describes community action for vulnerable children (see also Phiri, Foster, and Nzima 2001).

Microeconomic Strengthening

Many of the problems of AIDS-affected children and families result from their deteriorating economic situation. HIV/AIDS-related illness and death lead directly to economic problems that undermine children's well-being in a variety of ways (see Figure 1.2 in the Introduction). Consequently, improving the ability of vulnerable households to support themselves is fundamental. "Economic strengthening," however, is easier said than done. It is probably safe to say that all the major child-focused development organizations have had significant experience with failed

income-generating projects. The challenge, then, is to implement approaches that work and that can be replicated with reasonable consistency. Typically, what seem most likely to fail are group income-generating projects whose profits are intended to benefit vulnerable children. They are very difficult to sustain when they are run only by volunteers, and profits, if any, are generally quite limited. What shows much more promise are microfinance services and savings mobilization approaches that enable participants to carry out their own individual income-generating activities for the benefit of their own households (Donahue 2002: 5).

Most microfinance programs do not specifically aim to benefit children, although children typically do benefit. Evaluations (Adelski et al. 2001; Barnes 2002; IFAD 2002; Tumushabe 1999; Wright et al. 1999) show that women who participate in microfinance programs spend most of their profits on household needs such as their children's school expenses, health care, and food. The Uganda Women's Effort to Save Orphans (UWESO) program, however, has shown that targeting vulnerable children is possible in a financially sustainable program (see Figure 10.4).

Microeconomic interventions are needed for the majority of vulnerable households, but children and families at the very bottom who have already slipped into destitution need immediate, direct assistance. Their community, with some outside support, is in the best position to provide such help.

The economic stability of the entire community requires attention where HIV/AIDS is widespread. If too many families are allowed to become destitute, the community safety net will be overwhelmed. Effective microeconomic interventions that help stabilize household incomes can reduce the number of people who need immediate relief as well as increase the ability of poor and less-poor households to help those more vulnerable than themselves. Sustaining the capacity of families and communities to cope with the impacts of HIV/AIDS requires ongoing interaction between community mobilization and capacity-building activities, on one hand, and interventions that build household and community economic resources, on the other. Figure 10.4 makes this point, indicating that microeconomic strengthening and community mobilization are complementary approaches, both of which are necessary. Chapter 2 describes approaches to microeconomic strengthening.

Other Development Interventions

Appropriate development interventions can be targeted to geographic areas where families and communities are having the greatest difficulty protecting and providing for their most vulnerable children. For example, one of the recommendations of an assessment conducted in Uganda (Alden, Williamson, and Salole 1991) was to upgrade roads linking villages

While evaluations have shown that microfinance programs can help households in areas affected by HIV/AIDS to better meet basic expenses, the large majority did not aim for this goal. They set out simply to provide saving and credit services (and in some cases other services, such as microinsurance) to poor people in a sustainable way without specific social goals. The Uganda Women's Effort to Save Orphans (UWESO) Savings and Credit Scheme is an exception. Founded by the First Lady of Uganda, Madame Janet Museveni, UWESO started in 1986 making charitable responses to orphans of Uganda's years of armed conflict and brutal repression. By the early 1990s, increasingly, it was responding to children orphaned by AIDS. By 1994, through grants and donations, it was paying school fees for about five thousand orphans.

Recognizing the massive and growing task it faced, UWESO began to seek a more sustainable way to respond to orphan's needs. Initially, it tried funding group income-generating activities, but as many organizations have found, the rate of economic success was very low. Then UWESO tried starting small revolving-credit schemes, but these did not prove sustainable. In 1996, UWESO took a new tack and initiated its Savings and Credit Scheme, targeting households caring for orphans and using a village banking approach complemented with health and other training. As of 2002 some one hundred thousand children were receiving ongoing benefits from the program. Evaluations have found that children of school age are in school, the quality and frequency of meals has improved, and that between 1999 and 2003 there has been substantial improvement in the well-being and economic circumstances of participating households. The loan repayment rate has been 95 percent.

Women in some of UWESO's village banking groups also benefit from information and training in health, household, and social issues. Some of the topics include business skills, improved agricultural methods, HIV/AIDS, children's rights and protection, nutrition, water and sanitation, and property rights.

Sources: IFAD 2002; Tumushabe 1999; Ntambirweki, Pelucy. "The UWESO Savings and Credit Scheme (USCS), Uganda," in White, J., *Facing the Challenge: NGO experiences of mitigating the impacts of HIV/AIDS in sub-Saharan Africa*, final draft. Natural Resources Institute, University of Greenwich, UK, November 2002; Tumushabe/], "Quantitative Assessment of the Impact of The UWESO Development Programme," (Draft Report), Department of Population Studies, Institute of Statistics and Applied Economics, Makerere University, 2004.

FIGURE 10.4. Microfinance with a Difference: The UWESO Program in Uganda

to markets. Roads had deteriorated badly over the country's years of misrule and civil war. In a city market, the staple plantain cost ten times what it would bring in a more remote village due to transportation difficulties and the related breakdown in agricultural marketing systems.

In that situation, upgrading roads was one of the measures that offered good possibilities for improving the care of orphans in struggling communities. In other situations, supporting key agricultural inputs or tools, establishing new market linkages, and a variety of other development

interventions might be effective ways of improving the economic situation of families and communities.

In most countries women bear the major burden of caring for the ill and for orphans, in addition to most household tasks and many key economic activities. Development interventions that women identify as being important deserve particular attention in mitigating the impacts of HIV/AIDS. Examples might include improving access to safe water to reduce the amount of time and effort required to carry it, supporting collaborative, community-based childcare to free women's time for economic activities, and introducing fuel-efficient stoves or planting fast-growing tree varieties to reduce the time and effort needed to gather firewood. Laws that strengthen and protect the rights of women to own land and for widows to inherit property also benefit their children.

Direct Services

Children and households who slip to the level of destitution need direct support, which is often provided by community residents or local religious groups. Formal programs that deliver direct services for orphans and vulnerable children (for example, repairing houses, paying school expenses, providing food and material assistance, and health services) are often run by NGOs or government agencies. Many service delivery programs have produced good results, but with limited geographic coverage and at a cost per beneficiary that is too high to reach more than a fraction of the vulnerable children and households.

Direct service delivery is needed in all countries, but because it is resource intensive it can be the principal type of response only in countries with a strong economic base, or in less-developed countries during the early stages of an HIV/AIDS epidemic when fewer children are affected. As the number of children made vulnerable by HIV/AIDS escalates in a poorer country, the priority must be to shore up family and community capacities to protect and care for vulnerable children. This can keep to a manageable level the number of children whose survival and well-being depend on the ongoing delivery of direct services.

Support Grants

Some developing countries with high HIV prevalence are using household-level support grants to help vulnerable households to provide more adequately for especially vulnerable children. A working paper from South Africa concluded:

[T]he most equitable, accessible and appropriate mechanism for supporting children in the context of the AIDS pandemic would be through the extension to all children of the Child Support Grant mechanism that is currently in place,

and for the means test that restricts children's access to be removed. Progressive implementation of a universal Child Support Grant should be based not on providing grants in the interim to particular categories of children (such as orphans) but rather on drawing more impoverished children - irrespective of their parental circumstances - into the social security 'safety net' (Meintjes et al. 2004).

A separate study in South Africa, which included a total of 5,000 households in three provinces, found that over half of the income of these households came from current Government grant programs, old age pensions being the most significant source. Twenty-eight percent of the households were receiving child support grants (Vermaak et al. 2004).

The Progres program in Mexico is receiving attention as a model for possible adaptation in countries with a large number of orphans. Targeting poor households with poor villages, Progres benefits more than 20 million people through conditional cash grants. Selected households can receive a monthly cash grant for each child in grades three through nine who is in school and who attends at least 85 percent of the time. Each household is also eligible for an additional nutrition grant, conditional upon each child receiving two to four health check-ups per year, each adult having an annual check-up, and any pregnant women receiving seven pre- and post-natal checkups. The results have included increase in secondary school enrollment of more than 70 percent, a decrease of at least 20 percent in illness among children under five years of age, and a 45 percent reduction in the severity of poverty (Filmer n.d.).

Providing a large number of household support grants is beyond the means of many of the poorer countries without extensive external support, but some countries with a relatively strong economy, like South Africa and Botswana, are already using this mechanism as part of their response to the needs of orphans and other vulnerable children. Where such an approach can be sustained at scale, it is an effective way to provide support.

Activities to Promote Psychosocial Well-being

Psychosocial distress is less tangible than the material problems many AIDS-affected children suffer, but concerned organizations increasingly are addressing these issues. Enabling a family to cope more effectively with the material problems they face is a major step toward helping them deal with their psychosocial distress, but it is not enough. Effective measures to address psychosocial needs do not necessarily require separate programs; they should be incorporated into all activities for children and families affected by HIV/AIDS.

Interventions with psychosocial benefits include:

- Helping HIV-positive parents create memory books to assist them in talking with their children about important aspects of their shared past to deal with problems related to increasing illness, and to ensure children's future care.
- Enabling children to stay in school.
- Keeping orphaned siblings together by enlisting support from families and communities.
- Encouraging religious observances or traditional ceremonies to help heal grief and promote social integration.
- Training teachers to recognize and respond supportively to children's withdrawal or disruptive behavior.
- Encouraging and supporting communities to conduct structured recreation, art, cultural, and sports activities that enable isolated orphans and other vulnerable children to integrate socially.
- Organizing regular home visiting for orphans and children whose parents are ill.
- Reducing stigma and discrimination associated with HIV/AIDS
- Providing counseling services for children who are not responsive to other community-based interventions.

Chapter 4 addresses psychosocial issues and interventions.

HIV/AIDS Prevention, Treatment, and Care

While it is beyond the scope of this chapter to deal substantively with the wide range of approaches to prevention, treatment, and care related to HIV/AIDS, these services are directly relevant to the well-being of orphans and vulnerable children. Preventing HIV infections prevents orphaning. Treatment and care prolong the lives of HIV-positive parents and this is one of the most important ways to help their children. What is addressed here is the need for better integration of prevention and care activities.

Among HIV/AIDS care efforts there has been increasing attention to coordination and integration of home-based care for people living with HIV/AIDS and support for orphans and vulnerable children. Programs providing care and treatment for people living with HIV/AIDS have direct opportunities to identify the needs of children in the same household. Also linking care and prevention activities seems particularly relevant for children and adolescents. Teenagers frequently show a willingness and capacity to organize and address community problems. For example creating a framework in which older children and adolescents meet some of the emotional or daily living needs of orphans or people living with AIDS

provides opportunities to convey and reinforce HIV-prevention messages among participants, as well as benefitting those assisted.

Because families and communities are the first line of response to HIV/AIDS, programmatic interventions must be organized in ways that make sense in terms of people's day-to-day needs and struggles. Unfortunately, the focus of HIV/AIDS programs often has more to do with the skills of the professionals planning and managing them than it does with the problems the interventions are intended to address. For example, HIV prevention programs are typically planned by public health specialists, home-based care programs by medical service providers, programs for orphans by social welfare specialists, and microeconomic interventions by relevant specialists. Often these programs are quite separate, but the people on the front line do not categorize their lives in this way. Interventions for care or prevention, if they are to be effective, must be integrated in ways that make sense in terms of the daily realities of those most affected.

SCALING UP AND SUSTAINING RESPONSES

Because the number of children orphaned by AIDS can be expected to increase and remain high for decades, responses must match the scale of these impacts and be sustained indefinitely. This is not to say that an individual program should attempt to achieve country-wide coverage. But interventions must do so collectively, and available resources must be apportioned effectively among them.

One implication of the need to identify, scale up, replicate, and sustain effective interventions is that much more attention must be given to the per capita costs of effective interventions (see Figure 10.5). It is essential to develop affordable measures that can significantly improve the survival and development of vulnerable children and that can be replicated on the same scale as the pandemic's impact.

The only realistic way to scale up is for agencies and groups to develop a collective set of responses, including grassroots initiatives, larger NGO-supported programs, action by faith communities, and national development initiatives and policies. At each level of society, from the village to the nation, concerned individuals, groups, and agencies must come together, analyze needs and capacities, and find ways to collaborate to secure the protection and care of the most vulnerable children. Each country and community must review and consider its own situation and build its own set of responses, and committed leadership is needed at every level to make this happen. There is no viable alternative to this strategy, and it is beginning to materialize.

Countries in Africa are starting to conduct national situation analyses, develop national policies and plans of action concerning orphans and vulnerable children, and develop networks through which they can

The strategic importance of basic cost-per-beneficiary analysis was highlighted during a program assessment in Malawi (Williamson and Donahue 1996). All of the program's activities were relevant to the problems of AIDS-affected children and families. They included health care needs, education, training, and psychosocial needs of children, as well as training in home-based care, support for gardening and other income-generating activities, and microfinance services. The staff of the program considered it to be community-based because many of its activities were being carried out by community volunteers. It became evident during the assessment, however, that the ongoing participation of the volunteers depended on the continuing involvement of the sizable NGO staff and the material inputs that the program provided. The NGO's plans to shift the program to another geographic area seemed likely to result in the collapse of the activities that had been started in the initial area of operation. Further, the cost per beneficiary was too high for the program to be scaled up significantly. Taking these considerations into account, the program's leadership decided to revise it radically, and they began a community mobilization approach through which less costly, sustainable, and community-owned and managed activities were initiated.

FIGURE 10.5. Considering Cost per Beneficiary

exchange information and find ways to work together on an ongoing basis. By late 2003, of the forty-six sub-Saharan countries, twenty have carried out situation analyses concerning orphans and vulnerable children, the six had developed a response policy, and seventeen had established a coordination mechanism (UNICEF 2003: 51). In addition to the obvious need for such action, a motivating force has been the goals concerning orphans and vulnerable children established by the UNGASS on HIV/AIDS in the Declaration of Commitment (United Nations 2001). Technical guidance and opportunities for information exchange are being provided through sub-regional workshops on orphans and vulnerable children organized by UNICEF, USAID, and other organizations.

Much remains to be done, however. In particular, each country needs mechanisms to channel technical, material, and financial resources as well as essential information to the community groups on the front line of response. Initially, a collaborative national response may resemble more a patchwork quilt that is continually being revised and repaired than a neat organizational structure. But the central issue will be whether the various bodies manage collectively to make a positive difference in the lives of the most vulnerable children and families.

TARGETING RESPONSES

Scaling up requires targeting responses to improve the well-being of the most vulnerable children and families and using available resources as

effectively as possible. Resources may not be sufficient for even cost-effective programs to be uniformly implemented and sustained throughout a country. Targeting resources directs them where they are most needed, gathering information for subsequent targeting should be part of a situation analysis.

There are two stages of targeting. The first is to identify and direct financial and material resources to the geographic areas where families are having the greatest difficulty protecting and providing for the care of their children. This requires the use of data indicating the prevalence of problem conditions and responses, broken down to the district level or a lower administrative level, and might include rates of orphaning, adult mortality, infant mortality, malnutrition, school dropouts, income levels, and other poverty measures. Rates of children whose parents both have died can be used to identify areas where an HIV/AIDS epidemic is more advanced. A census or major health survey provides an opportunity to generate data to aid in targeting.

Targeting also includes mapping the availability of key services to address such questions as: where are interventions already underway; how adequate are these interventions; and where is the mismatch greatest between problems and existing responses? Such data must also be tested by review on the ground and consultation with people in the communities where problems appear to be greatest.

The second stage of targeting depends even more heavily on people in the most affected areas who can say which of their many problems concern them the most. They are also in the best position to identify the children and households who are at greatest risk. The most vulnerable members of a community are the least able to make their needs known, and local residents generally understand much better than outsiders what factors indicate serious vulnerability. Through a participatory process, they can identify locally relevant indicators of vulnerability and use these to assess relative levels of need among children and households. For example, communities have identified such factors as the following:

- whether either or both parents are living and provide care,
- age and health of the guardian,
- whether there is an adult guardian,
- age and sex of the children,
- whether the children are in or out of school,
- household size,
- health problems,
- loss of home or possessions,
- separation of siblings,
- how frequently a cooking fire is seen at a household,
- quality and frequency of meals,

- past and current economic activity,
- receipt of external support, and
- access to arable land.

Local targeting is most effectively done by communities that are already mobilizing and using their own resources to address local needs: They are very careful to direct locally generated resources to the children and households they are most concerned about. Competition and other problems can arise, though, when external resources are offered and local residents are asked to decide how to distribute them. Community groups that have already begun to use local resources to assist those about whom they are most concerned are better able to channel external resources effectively. Effective targeting also requires transparency. Local groups can best stimulate broad community participation and support when they are open about their aims and activities. Likewise, any external body that provides support for a local initiative is well advised to let the community at large know what resources it has provided and for what purpose, so residents and leaders can hold accountable those responsible for allocating and managing the resources provided.

MONITORING, EVALUATION, AND RESEARCH

The unprecedented characteristics of the HIV/AIDS pandemic necessitate ongoing monitoring of its impacts, evaluation of interventions, and research on strategic issues. To ensure that interventions actually make a difference in the lives of vulnerable children and families, their results must be measured. The findings, in turn, provide a basis for adjusting interventions to make them more effective and for deciding how best to use resources. These mechanisms should include participatory appraisal methods that community residents can use to measure the local impacts of HIV/AIDS and the effectiveness of their responses.

It is also important to identify within a country those NGO, university, and private-sector groups that can be called on to undertake short-term research and produce quick, practical reports on specific issues. Examples of possible strategic monitoring and research issues include the following:

- Develop child and community vulnerability indices to use in mapping and setting geographic priorities for interventions.
- Identify the processes, approaches, and models most suited to urban, periurban, or rural communities and different farming systems.
- Create ways that home-based care activities, especially those involving children and youth, can contribute to HIV prevention.
- Monitor impacts of HIV/AIDS on family and community economic coping strategies.

BUILDING POLITICAL, PUBLIC, AND DONOR SUPPORT

The safety, well-being, and development of a massive and growing number of African children are progressively being undermined by HIV/AIDS. Serious, concerted action is finally beginning to emerge in the most affected countries of that region. It is imperative that the countries in Asia, Central and Eastern Europe, the Caribbean, and Latin America do not make the mistake of most African countries by avoiding the issue until it reaches dramatic proportions. The UNGASS goals for orphans and vulnerable children have been agreed on by all countries and they call for serious, concerted action now. The only hope for an adequate and effective response lies in planned, collaborative action by all parties. Policymakers, community leaders, religious organizations, donors, the academic community, and the public all must play a role in each country to piece together and maintain an effective national response.

Generating increased awareness is essential but not sufficient; it will stimulate sympathy but probably little action. Awareness-raising must be linked with efforts to generate a broadly shared sense of responsibility to support and protect those affected by HIV/AIDS. It is important to convey a clear vision of how to help affected children and families and to identify the concrete steps necessary to make this happen.

A participatory national situation analysis, carried out jointly by key bodies in government and civil society, can be the first step in mobilizing action. This kind of process can generate information needed for broad social mobilization as well as for specific program and policy development. A campaign to sensitize the public should involve leaders and well-known individuals who can amplify and transmit key information and messages. This may include government leaders, representatives of the media, religious leaders, and popular sports and entertainment figures. In Zambia, for example, journalists formed the Media Network for Orphans and Vulnerable Children. National leaders must find the wisdom and courage to speak out clearly and often - not only about the threats posed by HIV/AIDS, but also about what is being done and what remains to be done.

CONCLUSION

Families and communities are the first line of response to children affected by HIV/AIDS. Millions of people struggle every day to survive and to provide whatever care they can to their vulnerable children and ill family members. But their resources are limited and many cannot by themselves provide adequate care, protection, and support. Families and communities cannot win this fight alone and many desperately need external assistance. Mobilizing communities and strengthening household economic and caring capacities can be the foundation of effective, sustained national

responses. External assistance and capacity building can enable communities to expand their activities incrementally as their capacities grow. Significant programmatic and policy action and planning are also needed to piece together an adequate national response. Governments must fulfill the right of every child to attend school and to access basic services, and governments also have the ultimate responsibility to ensure children's protection. Approaches to HIV prevention, care, and treatment that have been shown to work must be expanded and replicated. Better forms of family and community-based care must be greatly expanded to ensure protection and nurturing care for any child who slips through family and community safety nets. Each of us must recognize the urgency of these tasks, find ways to work together, and do it now.

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References

- Adelski, E., P. Bourdeau, J. B. Doamba, T. Lairez, and J. P. Ouedraogo. 2001. Final impact evaluation report on development activity proposal: 1997-2001. Ouagadougou: Catholic Relief Services/Burkina Faso, May i.
- Alden, J., J. Williamson, and G. Salole. 1991. Managing Uganda's orphans crisis. Report prepared for Displaced Children and Orphans Fund, USAID.
- Alien, H. 2002. CARE International's Village Savings and Loan Programmes in Africa: Micro Finance for the Rural Poor that Works. CARE, Tanzania, <http://www.kcenter.com/care/edu/CARE20Publications.htm>
- Alien, H., P. Koegler, and J. Rushawa. 2002. End of term evaluation of Kupfuma Ishungu Rural Microfinance Project (RMFP), Zimbabwe. CARE Zimbabwe, Harare.
- Barnes, C. (with E. Keogh, N. Nemarundwe, L. Nyikahadzoi, and E. Weiss). 2002. Microfinance and households coping with HIV/AIDS in Zimbabwe: An exploratory study. Horizons Final Report. Washington, DC: Population Council, September. <http://www.eldis.org/static/DOCi3059.htm>
- Donahue, J. 2002. Children, HIV/AIDS, and poverty in southern Africa. Paper presented at the Southern Africa Regional Poverty Network Conference, Pretoria, April 9-10.
- Donahue/ J., and J. Williamson. 1999. Community mobilization to mitigate the impacts of HIV/AIDS. Washington, DC: USAID Displaced Children and Orphans Fund, September i. <http://www.dec.org/pdf/-docs/pnacjo24.pdf>
- The framework for the protection, care, and support of orphans and vulnerable children living in a world with HIV and AIDS. 2004. Prepared by The Global Partners Forum for Orphans and Vulnerable Children, convened and led by UNICEF, July Available at <http://www.unicef.org>

- Hepburn, A. 2001. Primary education in eastern and southern Africa: Increasing access for orphans and vulnerable children in AIDS-affected areas. Report prepared for the Displaced Children and Orphans Fund, USAID, Terry Sanford Institute of Public Policy, Duke University, June. Available at <http://www.usaid.gov/IFAD> (International Fund for Agricultural Development).
2002. Mid-term review of the UWESO Development Programme (UDP): Implemented by Uganda Women's Effort to Save Orphans (UWESO), Financed by the Belgian Survival Fund (BSF) through the International Fund for Agricultural Development (IFAD). November-December.
- Meintjes, H., D. Budlender, S. Giese, and L. Johnson. 2004. Social security for children in the context of AIDS: Questioning the State's response. *AIDS Bulletin of the Medical Research Council of South Africa* 13(2):i-9.
- Nampanya-Serpell, N. 1999. Draft report for the Displaced Children and Orphans Fund, USAID/ on cost-effectiveness of interventions to benefit orphans and other vulnerable children.
- Phiri, S. N., G. Foster, and M. Nzima. 2001. 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. Washington, DC: Displaced Children and Orphans Fund, USAID. Available at http://www.usaid.gov/our-work/humanitarian_assistance/the-funds/pubs/ovc.html
- Sikwibele, A., C. Mweetwa, and J. Williamson. 2001. A midterm review of the Scope-0 VC program in Zambia: Conducted June 18-29, 2001. USAID/ Lusaka/ Zambia.
- Tumushabe/ J. 1999. UWESO Savings and Credit Scheme (USCS) evaluation report. Uganda Women's Effort to Save Orphans/ May. (Confidential report.)
- UNICEF. 2003. Africa's orphaned generations. New York: UNICEF, November. <http://www.unicef.org/publications/africas-orphaned-generations.pdf>
- United Nations. 1989. Convention on the rights of the child. UN General Assembly Res. 44/25, UN GAOR, 44th sess., 41st plen. mtg./ annex, UN Doc. A/RES/44/25 (December 12). Geneva: United Nations, <http://www.unhcr.ch/html/menu3/b/k2crc.htm>
- _____. 2001. Declaration of Commitment on HIV/AIDS. UN GA 26th Special sess./ UN Doc. A/Res/S-26/2 (2001) June 25-27. Available at <http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>
- USAID, UNICEF/ and UNAIDS. 2002. Children on the brink 2002: A joint report on orphan estimates and program strategies. Washington/ DC: TvT Associates/The Synergy Project/ USAID. <http://www.unicef.org/publications/pub-children-on-the-brink-en.pdf>
- _____. 2004. Children on the brink 2004: A joint report of new orphan estimates and a framework for action. New York: USAID. Available at <http://www.unicef.org>
- USAID, UNAIDS, WHO, UNICEF, and the Policy Project. 2004. Coverage of selected services for HIV/AIDS prevention, care and support in low and middle income countries in 2003. June, 84 pages, <http://www.policyproject.com/pubs/generalreport/CoverageSurveyReport.pdf>
- Vermaak, K., N. Mavimbela, J. Chege, and E. Esu-Williams. 2004. Challenges faced by households in caring for orphans and vulnerable children. Research Update. Washington, DC: Population Council/Horizons and Frontiers.

Williamson/ J./ A. Cox/ and B. Johnston. 2004. Conducting a situation analysis of orphans and vulnerable children affected by HIV/AIDS: A framework and resource guide.

Washington, DC: Office of Sustainable Development/ Bureau for Africa/ USAID/ February.

Williamson/ J./ and J. Donahue. 1996. Developing interventions to benefit children and families affected by HIV/AIDS: A review of the COPE program in Malawi for the Displaced Children and Orphans Fund. Washington, DC: Displaced Children and Orphans Fund, USAID.

Weight, G. A. N., D. Kasente, G. Ssemogerere, and L. Mutesasira. 1999. Vulnerability, risks, assets, and empowerment: The impact of microfinance on poverty alleviation. Commissioned in preparation for the World Development Report 2001, MicroSave-Africa and Uganda Women's Finance Trust, March. <http://www.undp.org/sum/MicroSave/ftp-downloads/UWFTstudyFinal.pdf>