

# **Finding a Way Forward**

Principles and Strategies to Reduce the Impacts of AIDS on Children and Families

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# Contents

Acronyms .....	2
Introduction .....	3
Impacts on Children and Families .....	3
Re-Conceptualizing the Issues .....	6
Scale and Duration .....	7
An Invisible Disaster .....	9
Analyzing the Situation .....	10
Making a Strategic Response .....	13
Intersectoral Collaboration .....	14
A Policy Framework .....	14
Criteria for Programmatic Interventions .....	15
Community Mobilization and Capacity Building .....	17
Microfinance Services .....	19
Other Development Services .....	20
Education .....	21
Sustainable Relief .....	22
Why Institutional Care Is Not the Answer .....	23
Scaling Up Sustainable Responses .....	26
Cost-Effectiveness .....	26
Structures for Collaboration .....	27
Targeting .....	27
Monitoring, Evaluation, and Research .....	29
Integrating Care and Prevention .....	29
Building Political, Public, and Donor Support .....	30
Notes .....	32

## Acronyms

CBD	Community-based development
COPE	Community-based Options for Protection and Empowerment
CRC	United Nations Convention of the Rights of Children
CRS	Catholic Relief Services
DCOF	Displaced Children and Orphans Fund
FINCA	Foundation for International Community Assistance
GNP	Gross National Product
HBC	Home Based Care
HDI	Human Development Index
HPI	Human Poverty Index
IEC	Information Education Communication
NGO	Nongovernmental Organization
PLWA	People living with AIDS
SCF (UK)	Save the Children Fund (United Kingdom)
STD	Sexually Transmitted Diseases
UNDP	United Nations Development Program
UNICEF	United Nations Children's Fund
UNPOP	United Nations Population Program
USD	U.S. Dollars
UWFT	Uganda Women's Finance Trust
WHO	World Health Organization

## **Introduction**

Developing effective interventions to mitigate the devastation HIV/AIDS causes among children and families requires giving careful attention to both ends of the epidemic's spectrum of impacts. It is vitally important to understand the problems on a human scale, what happens to parents, children, and orphans' guardians. But this perspective, by itself, is not adequate to guide a strategic response to these problems. It is also essential to keep in mind the magnitude and scale of the HIV/AIDS pandemic and its collective impacts.

Developing programs that significantly improve the lives of individual children and families affected by HIV/AIDS is relatively easy with enough resources, organizational capacity, and compassion. Vulnerable individuals and households can be identified, health services can be provided, school expenses of orphans can be paid, food can be distributed, and supportive counseling can be provided. Such interventions meet real needs, but the overwhelming majority of agencies and donors that have responded so far have paid too little attention to the massive scale of the problems that continue to increase with no end in sight. As programs to date have reached only a small fraction of the most vulnerable children in the countries hardest hit by AIDS, the fundamental challenge is to develop interventions that make a difference over the long haul in the lives of the children and families affected by HIV/AIDS at a scale that approaches the magnitude of their needs. Throughout this report, in keeping with the United Nations Convention on the Rights of the Child, the term "child" is used to refer to all persons below the legal age of majority: infants, children, and adolescents.

## **Impacts on Children and Families**

HIV/AIDS is causing unprecedented threats to children's well-being and safety, and there is no road map to guide responses. A child's vulnerability begins to increase long before a parent dies. The common impacts include deepening poverty, such as pressure to drop out of school, food insecurity, reduced access to health services, deteriorating housing, worsening material conditions, and loss of access to land and other productive assets. Psychosocial distress is another impact on children and families, and it includes anxiety, loss of parental love and nurture, depression, grief, and separation of siblings among relatives to spread the economic burden of their care.

In poor households, HIV-related illness leads directly to household economic problems as adults fall ill and cannot work, available resources are used for treatment, and other family members divert their time to provide care. As a household's income and productivity falls and its expenses mount, children often drop out of from school because their families are unable to pay for fees, books, and uniforms. Children often take over adult work responsibilities and provide care for their ailing parents. Cutting short their education reduces future economic prospects for the children and for their families.

Household food security is also undermined as income and productive capacity fall. Rural households often shift from producing and consuming more nutritious types of food, such as maize, to less nutritious, but easier-to-produce types, such as cassava. Animals may also be sold to meet other economic needs, reducing dietary intake of milk, meat, and eggs. If the economic slide continues, rural families may be forced to sell their productive assets, such as land, tools, and draft animals, which seriously reduces their prospects for economic recovery. Illness also leads to problems with shelter, such as a reduced ability to maintain and repair housing. Wage earners who can no longer work may lose housing that was an employment benefit.

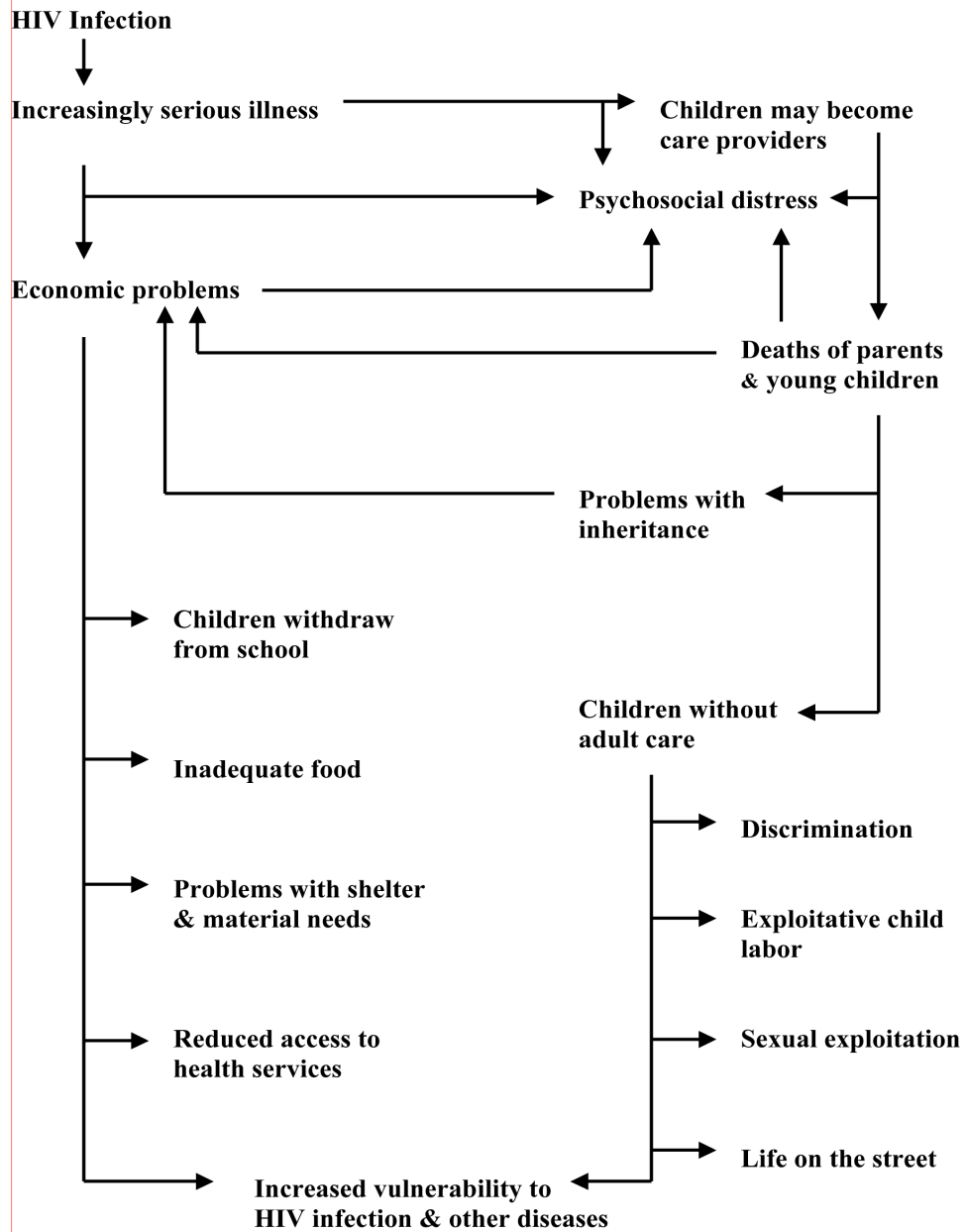
This economic slide reduces a household's access to health services at a time when these are increasingly needed. At the same time, youth in the family may be particularly vulnerable to HIV infection because they are economically and emotionally vulnerable to sexual exploitation.

The death of a parent brings additional problems. Funeral costs consume more resources, and afterwards widows and children may be left destitute if relatives claim the dead parent's property but ignore their traditional responsibilities to care for his widow and orphans. In many patrilineal societies, when a man dies his family may claim his property since they had helped pay the bride price so he could marry. This can leave his survivors without the means to support themselves.

After the deaths of both parents, siblings are often divided among several households within the extended family, compounding their grief and causing long-lasting emotional distress. Orphaned children may be treated as second-class members of their new households and be expected to do more work than the other children. Stigma associated with AIDS, orphans dropping out of school, and orphans working on the street reduces social support and intensifies psychosocial distress.

As HIV/AIDS moves through families, killing adults in their most productive years, elderly grandparents often become the primary care providers. Some children or adolescents become the heads of households while others leave abusive or destitute households to fend for themselves on the street. Even for those children in less extreme circumstances, psychosocial problems relating to loss and bereavement may affect behavior and development. Stigma associated with AIDS frequently compounds their emotional distress and vulnerability. Figure 1 provides an overview of the kinds of problems affecting individual children and families and how these problems interrelate.

**Figure 1. PROBLEMS AMONG CHILDREN AND FAMILIES AFFECTED BY HIV/AIDS**



In 1991, as such problems began to emerge through press reports and studies by nongovernmental organizations (NGO), the United States Agency for International Development (USAID) sent a team to assess the situation in Uganda in response to a request by the Ugandan Government. As a member of that three-person team, I took part in discussions of the situation with relevant ministries, helped identify relevant policies, and learned about the rapidly growing number of programs started by NGOs. Our team considered these to be the key areas for our attention. Then we visited communities in Rakai District at the epicenter of Uganda's HIV/AIDS epidemic.

The problems among orphans we had heard about were evident as we talked with children, grandparents, and other guardians and saw the fallow fields, empty houses, and recent graves. But we also began to see that we had been looking at the situation from the wrong perspective. Although press reports announced the imminent collapse of extended families, there were relatively few children on Kampala's streets, and child-headed households were very rare. Although households were under great stress, it was evident that there was no wholesale collapse of extended families, because the overwhelming majority of orphans were living within their extended families in their own communities. These families and communities were the first line of response. We saw that the Ugandan Government, NGOs, and others had an important role to play, but it was not to save isolated orphans. Its role was primarily to strengthen the capacities of families and communities to cope.

The pandemic has spread extensively since 1991. More children are being pushed onto the street, child-headed households are becoming more common, and extended families are under even greater stress. But even in the counties hardest hit, most orphans and other children made vulnerable by HIV/AIDS are still living within their extended families. Recognizing this is fundamentally important to developing effective interventions.

## **Re-Conceptualizing the Issues**

The way a problem is understood has a major influence on what is done about it. The starting point for effective responses to the impacts of the pandemic on children is recognizing that families and communities are the first line of response to HIV/AIDS. Whether outside bodies intervene or not, families and communities are going to be dealing with the impacts of HIV/AIDS, often with great difficulty. Consequently, interventions by governments, international organizations, NGOs, religious bodies, and others will have significant, sustainable impacts on children's vulnerability and well-being to the extent that they strengthen the ongoing capacities of affected families and communities to protect and care for vulnerable children. Building family and community capacities is not enough, but it must be the foundation for addressing the impacts of HIV/AIDS on children.

If the coping capacities of families and communities seriously affected by HIV/AIDS are not reinforced, then government, NGO, and other direct service programs will be overwhelmed by the number of children slipping through the basic social safety nets. USAID, in *Children on the*



*Brink*, estimates that in nine sub-Saharan Africa countries at least one of every five children will have lost one or both parents by the year 2000, with AIDS being the major cause of death.<sup>1</sup> An increasing number of children are being pushed by poverty, parental illness, and death onto the street or are struggling on their own to scrape by in rural villages. Family and community safety nets are not sufficient for some children, and child protection and care interventions are needed if the most vulnerable children are to survive and have a chance for healthy development. But with the large and growing number of orphans, there will not be enough resources available to make direct service delivery the primary type of intervention for the majority of orphans and children made vulnerable by HIV/AIDS.

Another implication of families and communities being the first line of response to HIV/AIDS and its impacts is that interventions must be organized and delivered in ways that make sense in relation to the day-to-day needs and struggles of HIV/AIDS-affected households. As they have developed from the national to the community level, programmatic responses to HIV/AIDS largely fall into the categories of prevention, home-based care for those who are ill, and orphan care.

The people on the front line intended to benefit from these activities, however, do not segment their lives into such boxes. This way of organizing programs has more to do with the skills of the professionals planning and managing them than it does with the problems these interventions are intended to address. Figure 1 shows the web of cause and effect relationships that exists among the problems with which families are trying to cope. Generally, there is little if any coordination among the standard categories of HIV/AIDS-related programs. Interventions for care or prevention, if they are to be effective, must be integrated in ways that make sense in terms of the day-to-day realities of those most affected.

## **Scale and Duration**

If action to respond to the impacts of HIV/AIDS is going to make a significant difference, it must match the scale and duration of the pandemic. Estimates of the number of children who have been or will be orphaned by AIDS vary. USAID has estimated that in 23 countries seriously affected by HIV/AIDS, by 2000 almost 35 million children below the age of 15 will have lost either or both parents, with AIDS being the major cause.<sup>2</sup> UNAIDS estimates are lower and limited to children whose mothers have died because of AIDS—they estimate there will be 8.2 million children orphaned due to AIDS by 1997. UNICEF has pointed out that in 1998 two million Africans died of AIDS, which is 10 times greater than the number who died as a result of armed conflict. Current estimates for Zambia, for example, are that between 15 and 34 percent of all children have lost one or both parents, with AIDS being the primary cause.<sup>3</sup>

These figures are staggering to contemplate, but it is clear that the scale of orphaning is very large and getting larger and that it will continue to increase and remain high for a very long time. Figure 2 reflects this pattern and suggests that those who respond effectively will have to sustain their interventions over a period of decades. Even the development of an effective vaccine for

HIV, at best some years away, would still leave a large number of orphans in need of care.

Figure 2 available in hard copy only

Figure 2. From the UNICEF slide presentation, *Children in a World With HIV/AIDS: New Challenges New Choices*, September 1998

Dr. Peter Piot, Director of UNAIDS, put the issue in perspective in a speech in Johannesburg in November 1998, when he said, “We now know that despite these already very high levels of HIV infection the worst is still to come in southern Africa. The region is facing human disaster on a scale it has never seen before.”

The accuracy of different orphan estimates remains essentially little more than an academic issue, since in no country do the collective responses reach more than a fraction of the orphans and other children made vulnerable by HIV/AIDS. The scale of the problems children are experiencing is much larger than the interventions being implemented to address them, and there is yet no clear, shared vision of how these activities could be brought to scale. Programmatic action is extremely fragmented and coordination is very limited among the various governmental, civil society, international, and religious bodies that are responding to the impacts of AIDS on children and families.

Although 95 percent of the children whose mothers have died from AIDS-related causes live in Sub-Saharan Africa, the problems that HIV/AIDS is causing should not be mistaken for a uniquely African issue.<sup>4</sup> Africa has been the continent hardest hit by the pandemic—experiencing 80 percent of the world’s AIDS cases—and it has yet to see the worst. But impacts can be expected on an even larger scale in Asia, where the spread of HIV has been recent and swift.<sup>5</sup> Infection rates are rising in India with an estimated five million people already infected, more than any other country.<sup>6</sup> Cambodia, Myanmar, Vietnam, and other Asian countries have rapidly increasing epidemics. Since 1995 there has been a six-fold increase in the number of HIV infections in the former Soviet countries of Eastern Europe and Central Asia. In the United States, HIV rates and orphaning are increasing among poor urban and rural populations.

## **An Invisible Disaster**

Although the scale of the impacts of HIV/AIDS is immense, those impacts are difficult to observe and document because they occur slowly, one household at a time, and because the stigma associated with AIDS persuades many HIV-positive individuals to keep a low profile or deny their status. The stigma associated with HIV/AIDS and the consequent reluctance of most national leaders to speak out about the pandemic significantly contributes to the low visibility of its collective impacts. Even in communities that have been seriously affected for years by AIDS-related illness and death, residents frequently are unwilling to talk openly about AIDS. It is common for communities where one of every five adults is HIV positive not to identify AIDS as one of their major problems.

Actions to respond to the impacts of HIV/AIDS on children and families have also been limited because the pandemic is different from other emergencies and disasters. The effects of war and natural disasters are more sudden and dramatic and tend to overshadow the even greater devastation being caused by the pandemic. Because HIV/AIDS is a slow-onset disaster, HIV continues to spread, and the impacts of AIDS develop incrementally, family by family. In contrast to other epidemics and disasters, it mainly kills adults in their prime, and it does so during the years that their children need them the most. Because the HIV/AIDS pandemic is still relatively new and still evolving and expanding, the problems it creates for children are unprecedented and the nature and full extent of its future impacts are uncertain. There are no roadmaps to guide responses because we continually move into uncharted territory.

### **A Story**

The village elders were deeply troubled by what they had seen happening in recent years. Many more people were falling sick. No one respected the tradition of no work for three days after a funeral. Indeed, if they did, little work would be done because so many were dying, and there were so many more orphans than before. These children should be in the care of their uncles, but too many of the uncles have died. The grandparents, who should be enjoying the support of their children, are often forced to take care of the orphans.

The younger people see these things, but they do not understand them. They are so busy trying to just feed their families that they don't have time to think much about how things used to be or how they might be different.

The elders decided to call the people together. In front of them they made a fire. There were two pots of water, and one was placed on the fire till it became very hot. They called forward a young boy whom they had sent to catch two frogs. They told him to drop one of the frogs into the hot water. It jumped out of the pot. The other they told him to place in the pot with cool water and to put the pot onto the fire. Everyone watched, but nothing happened. The frog stayed in the pot as it gradually heated. An old woman came forward and with a big spoon lifted the frog out of the pot. It was dead. She asked the people to think about what they had seen, then she explained, "The first frog felt the hot water and jumped out to save himself. But the second one adjusted bit by bit as the water became gradually hotter, and before he decided to jump, it was too late."

The elders then talked about the changes that they were seeing in the village. The young people understood and began to talk about what they could do to protect themselves and their families from AIDS.

The magnitude of the problems caused by AIDS, the heart-wrenching devastation it wreaks on children and families, and the collective uncertainty about the way forward, have produced occasions of public hand wringing by leaders and periodic discoveries by the media that there are massive numbers of orphans. These responses, however, have not led to coherent, effective interventions that match the scale of the evolving disaster. It is imperative that governments, international organizations, religious bodies, nongovernmental organizations, and the public at large develop a clear perspective on the problems and challenges posed by the HIV/AIDS pandemic and that they develop collaborative responses. The scale of the problems is so large and the challenges so diverse and widespread, that no single body has the resources to make an effective, unilateral response. Broad collaboration is essential among a wide range of governmental, international, and civil society actors to define problems and address them in ways that will make a difference in the lives of the most vulnerable children and families.

Significant social, economic, demographic and other impacts of AIDS are emerging in the most-affected countries. Failure to address these effectively will undermine development and, potentially, social stability in these areas. As the growing number of disaffected; undereducated; and inadequately nurtured, nourished, and socialized young people grows, the most severely affected countries may face serious threats to their social and political stability and their economic functioning. Finding effective ways to mitigate the impacts of HIV/AIDS on children and families must become a top priority of national governments and international bodies.

## **Analyzing the Situation**

The nature and intensity of the family and child welfare problems caused by HIV/AIDS vary among communities and countries. Situation analysis and ongoing monitoring are essential to planning and implementing effective interventions. Actions intended to benefit children and families affected by HIV/AIDS must be based on a realistic understanding of their situation if they are to produce sustainable results on a significant scale. Situation analysis is a process of gathering and analyzing information to guide planning and action. It involves gathering information about the epidemic, its consequences, household and community coping responses, and relevant policies and programs. It concludes with analyzing the information gathered, identifying geographic and programmatic priorities, and making specific recommendations for action. Situation analysis provides a basis to make hard choices about how and where to direct available resources to benefit the most seriously affected children and families.

A situation analysis should be more than a technical exercise to generate information; it should help build consensus among key stakeholders. Collaboration to mitigate the impacts of HIV/AIDS becomes essential as an HIV epidemic spreads. Conducting a situation analysis as a broadly inclusive, highly participatory process provides a vital opportunity to bring together key participants—those already engaged and those who will need to be—and to identify in broad terms the best way forward. These might include relevant ministries, international organizations, donors, NGOs and their coordinating bodies, associations of people living with HIV/AIDS, religious bodies, women's associations, members of seriously affected communities, university

departments, civic organizations, the business community, or other concerned groups. If key stakeholders participate actively, they are more likely to feel ownership of and commitment to the findings of a situation analysis.

For a situation analysis to provide useful guidance on how problems among the most vulnerable children and families can be addressed effectively and at scale, it must produce information needed for geographic targeting and identify key interventions that can be implemented at scale and produce sustainable results. Even if cost-effective responses to the most critical needs of vulnerable children and families are developed rapidly, sufficient resources are not likely to be available for them to be uniformly implemented throughout a given country. A situation analysis should identify those geographic areas where families and communities are having the most difficulty protecting and providing for the most vulnerable children. This requires identifying any available census or reliable survey information on orphaning and adult mortality; considering the pattern of spread of the epidemic and its impacts on different farming systems and other economic activities; using health, nutrition, education, and other vulnerability indicators; and assessing the geographic reach and effectiveness of current services. Mapping such information can help identify geographic priorities.

Actions to address the impacts of HIV/AIDS differ from one community to another because the problems indicated in Figure 1 develop in different ways. Which problems develop in an area, their nature and intensity, and how people can cope with them largely depends on the local context. It influences where and why problems occur and their severity.

At least seven aspects of an area's context deserve particular attention: (1) The *epidemiological pattern* of HIV/AIDS in a country indicates the geographic areas in which problems are most likely to emerge. (2) *Demographic conditions* can significantly affect how an HIV/AIDS epidemic will evolve and the different possibilities for economic survival. There are, for example, many different issues between rural and urban areas. (3) *Social, cultural, and religious characteristics* potentially affect both problems and options for coping. For example, kinship networks that support affected families, ways orphaned children are traditionally provided care, and whether compassion or judgement is encouraged toward people living with HIV/AIDS and their families are significant factors. (4) *Knowledge and attitudes toward HIV/AIDS* influence the degree of stigma and discrimination, on the one hand, and the potential for effective in-home care, on the other. (5) *Economic activities* and systems can directly affect all HIV/AIDS-related problems. (6) Access to *basic services*, including education, health care, and child protection can significantly reduce problems. (7) *Laws and policies* can protect the inheritance rights of widows and orphans. They can sanction or prevent discriminatory practices.

These aspects of the context and the ways they interrelate should be given particular attention in a situation analysis. Identifying the most significant aspects of the local context is essential to plan effective interventions and adjust them as the situation changes. Identifying ways that the context causes and affects problems helps to identify opportunities for strategic interventions.

Even if there are no models to impose, there is much to be learned from one country to another about the ways that problems evolve and about potentially effective interventions. Each country should not focus only on its own situation. There is much that can be shared and learned across borders. A literature review that includes the “gray” literature of unpublished reports should be part of a situation analysis.

A situation analysis should lead to a working understanding of priority issues. It should generate credible technical information on the current and future magnitude of orphaning and other impacts of HIV/AIDS on children and families. For program heads and policy makers, it should provide clear answers to the question, “Why should I care about these issues?” Participating groups should work together to compile and analyze information on issues such as the following:

- The nature and pattern of the HIV/AIDS epidemic within the country;
- Trends in orphaning;
- The types and scale of current and projected problems;
- Household coping strategies;
- How knowledge and attitudes about HIV/AIDS affect these coping strategies;
- Implications of demographic patterns on the epidemic and concentrations of problems;
- Economic vulnerabilities and resources;
- Social, cultural, and religious influences and resources;
- Community support for AIDS-affected households;
- Availability and accessibility of existing services, including education, health, and social services; and
- Interventions that have the potential to be effective and sustained at scale.

Taking such information into consideration, participants must develop recommendations for specific actions. Simply making a wish list of things that should be done is not enough. So far as possible, participants should recommend what needs to be done and specify which body or bodies should be responsible within a specific time frame. In formulating their recommendations, it is important for participants to consider as a whole the situation they have described, and then to organize and integrate their recommendations, identifying priorities among them, resources required, specific responsibilities, and timing. If a situation analysis is to lead to effective decision-making, planning, and action, it must not become an end in itself, but a springboard for building consensus and momentum toward specific actions.

A system to monitor the impacts of AIDS on children and families should be one of the products of a situation analysis. The process should identify sources of information to be used for ongoing monitoring and produce a recommendation about who should be responsible for periodically compiling, analyzing, and disseminating such information. A situation analysis provides a valuable picture of the impacts of HIV/AIDS and responses to them, but conditions will continue to evolve along with the epidemic and other factors that influence poverty and vulnerability. The

situation analysis gradually becomes a less accurate representation of reality, so periodic monitoring is needed to help guide and adjust interventions.

## **Making a Strategic Response**

By itself, no single intervention will make a substantial impact on the full range of economic and psychosocial problems HIV/AIDS is causing among children and families. The problems are too many and varied. A planned and coordinated set of policy, social mobilization, and programmatic interventions by public sector and civil society actors is needed. This requires government leadership to develop a strategic response—leadership which, with few exceptions, has been absent.

For governments to mobilize and guide strategic responses requires that policy makers at every level of society understand the type of collaborative responses needed; advocate sustained, multisectoral commitment to the task; and use their policy and public leadership capacities to support these. Uganda, Thailand, and Senegal have shown that open, committed leadership can make a difference. In 1999, African heads of state pledged themselves to action in the new International Partnership against AIDS in Africa. It is hoped that they will follow through.

*Children on the Brink* identifies basic response strategies for planning a strategic response to the impacts of HIV/AIDS on children and families. The first of these strategies involves strengthening the capacities of the two primary social safety nets on which people in the developing world depend: the extended family and the community. Basic intervention strategies described in *Children on the Brink* include the following:

- Increase the capacity of families to care for vulnerable children.
- Increase the capacity of communities to support vulnerable children and households.
- Increase the capacity of children affected by HIV/AIDS to support themselves and younger siblings.
- Increase the capacity of the government to protect vulnerable children and provide essential services.
- Build an enabling environment in which it becomes easier for children and families to cope.

“Building an enabling environment” can include increasing the awareness and commitment of leaders and the public concerning children who are especially vulnerable, developing policies to guide action, establishing laws and policies that protect children and widows, reducing stigma and discrimination associated with HIV/AIDS, improving the programming capacities of key stakeholders and coordination among them, and monitoring the epidemic and its impacts.

## **Intersectoral Collaboration**

A strategic response requires involving the full range of actors and expertise relevant to the problems at the community level and developing mechanisms for ongoing collaboration. It should be guided by a policy framework; include mechanisms to channel resources effectively; and evolve through transparent, participatory cycles of assessment, planning, implementation, monitoring, and evaluation. Countries with advanced epidemics have increasingly recognized that HIV/AIDS is much more than a health issue. Agriculture, education, community development, and business sectors are being seriously affected as well. In the most seriously affected countries, the magnitude of the impacts of HIV/AIDS are far too large, varied, and interrelated for any single body to address unilaterally and adequately at scale. Information sharing and collaboration are needed among key government ministries, international organizations, donors, NGOs, religious bodies, the business sector, and the affected communities.

The scale of the impacts of HIV/AIDS on children and families are also too extensive for any organization or body concerned with development to ignore. Where an HIV epidemic reaches an advanced stage, all development gains and prospects are undermined. There is no alternative to collaboration.

## **A Policy Framework**

Governments have a responsibility, through laws, policies, and action, to establish a framework that supports the coping capacities of individuals and families and provides them with essential protection. This framework must be constructed with particular attention to the situation of children and women. The process of formulating laws and policies must be informed by an understanding of the situation and problems of people living with HIV/AIDS, children and families affected by it, and the potential for government action to have a significant impact.

Key elements of a framework to protect children and women include laws and effective structures for their implementation, such as provisions for the following:

- Prohibition of discrimination in health care, schools, employment, or other areas based on actual or presumed serostatus;
- Placement and guardianship for children who lack adequate adult care;
- Enactment and enforcement of laws ensuring women the right to own property;
- Protection of the inheritance rights of orphans and widows;
- Protection of children against abuse, neglect, and sexual contact with adults;
- Prohibition of harmful child labor;
- Elimination of barriers to orphaned children continuing their education; and
- Protection and support for street children.



## Criteria for Programmatic Interventions

Even with key actors collaborating under a clear policy framework, it is imperative that their interventions are proportionate to the scope and scale of an epidemic's impacts. In the developing countries most seriously affected by HIV/AIDS, most mitigation activities have fallen into two categories: the first is NGO programs whose paid staff deliver direct relief and development services to affected children and families, sometimes with the involvement of community volunteers. Many such programs have produced good results, but with relatively limited geographic coverage and at 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 1994, for example, I led a team that evaluated USAID-supported interventions to benefit orphans in Uganda. The team found that a significant amount of funding was going to NGOs to enable them to provide relief assistance and pay school fees. While interventions produced immediate benefits, we questioned whether USAID was prepared to continue such support at increasing levels year after year. We recommended that more attention be given to interventions whose benefits could be sustained.

Staff- and resource-intensive service delivery programs can be the principle type of intervention during the early stage of an HIV/AIDS epidemic or where a country's economic base is strong enough to sustain such approaches. Such activities include material assistance, free education or scholarships, foster care and adoption systems, center-based vocational education, and individual professional counseling. As the number of children made vulnerable by HIV/AIDS escalates, however, less-developed countries simply are not able to increase and sustain such labor- and resource-intensive approaches on a scale that matches needs. Such interventions will still be needed, but it is imperative to now shore up family and community capacities to protect and care for vulnerable children, thereby maintaining the number of children whose survival depends on individual social service interventions at a manageable level. The cost per beneficiary of programs through which paid staff deliver direct services to orphans is too high to reach more than a small fraction of the children made vulnerable by HIV/AIDS. Because of these higher costs, provision by social service personnel of material or financial support to individuals, as well as the provision of formal child placement services, must concentrate on the most vulnerable children—those without adult care who are unable to provide for their own needs.

A second category of intervention is grassroots community initiatives, which have produced good results at a low cost per beneficiary. There are many such examples. In 1994, Sue Armstrong and I described a number of them in Uganda and Zambia in *Action for Children Affected by AIDS*, and such interventions continue to emerge in the countries where the proportion of orphaned children has grown large.<sup>7</sup> Such initiatives are owned by the community groups that start them, and participants in them do not consider themselves to be volunteers in someone else's program. The participants have a personal sense of responsibility to help orphans and other vulnerable children in their community and "own" their group's initiatives.

Grassroots groups often make heroic efforts to identify extremely vulnerable children, monitor their individual situations, respond primarily with local resources to these needs, and in many cases to secure small amounts of funding or material support that they then use very efficiently. The problem with such efforts is that each generally reaches only a few children in a very limited geographic area and, collectively, their coverage is quite limited. They tend to be widely scattered, and they only emerge in a few communities. The programmatic challenge, then, is to develop ways to systematically mobilize such responses and to help communities sustain them over time.

A strategic approach requires as its foundation strengthening family and community capacities on a wide scale, as well as supplementary interventions for children and other vulnerable individuals who fall through those primary social safety nets. The kinds of interventions appropriate vary from one stage of an HIV epidemic to the next as it evolves, expands, and intensifies. Cost-effective, sustainable interventions must be scaled up to produce sustainable results on the scale that problems are occurring.

A key step is to carry out a systematic review of current policies and procedures in health, education, and social services to identify ways to improve access by HIV/AIDS-affected children and families. Available resources can be multiplied by using them to mobilize, strengthen, and support voluntary community responses. Considering scale, cost, and potential sustainability, there are advantages to working through organizations that already exist in many communities. Examples of such organizations include religious bodies, health services, community committees, schools, civic organizations, women's associations, labor unions, and cooperatives.

The child welfare challenges posed by HIV/AIDS impacts are unprecedented and daunting, but failure to address them would seriously undermine development efforts generally. How to address them is the critical question for the countries most seriously affected by HIV/AIDS. When considering possible interventions, a key consideration is how significantly each intervention can improve the ongoing coping capacities of families, communities, or vulnerable children. Interventions must be tailored to the particular problems of vulnerable children and to the particular circumstances in which they are living. Considering this, in countries with more advanced epidemics, interventions should have the following characteristics:

- Be directed to the most vulnerable geographic areas, communities, and population groups;
- Be targeted by each community to its most vulnerable children and households;
- Be effective in reducing the vulnerability of orphans and other vulnerable children;
- Be sustainable or achieve sustainable impacts;
- Have a low cost per beneficiary;
- Be widely replicable; and
- Be coordinated.

International experience to date indicates that community mobilization and capacity building,

coupled with state-of-the-art microfinance programs, show promise for meeting these criteria.

## Community Mobilization and Capacity Building

Community mobilization and capacity building are catalytic processes through which an outside agent first helps communities to identify what concerns them most, decide what they can do about these issues, and take action. Then there is follow through over time to improve needed skills and link communities with outside resources (training, information, or material, financial, or technical support). In some cases, these processes may also involve the outside agent directly providing limited amounts of resources to the community on an ongoing basis—but this cannot lead the process.

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

Effective mobilization is based on the community's ownership of the problem and a sense of responsibility to address it. It is *not* a matter of convincing people to take action by giving them resources or to work for free in someone else's program.

There is an extensive body of development literature indicating that communities can be mobilized when residents come together and collectively define strongly felt shared concerns and identify how they can address these concerns themselves.<sup>8</sup>

Programs in Malawi, Zimbabwe, and Zambia have shown that communities seriously affected by HIV/AIDS can be systematically mobilized to address the most urgent needs of orphans and other especially vulnerable children. These programs have shown that people at the grassroots level are not only concerned about the growing number of such children, but that they are also prepared to take responsibility for responding to them, primarily by using local resources.

Staff of **Zambia's Project Concern International**, together with Ministry of Community Development and Social Service personnel, have organized two district Orphans and Vulnerable Children (OVC) committees. In ethnically heterogeneous urban communities, they have helped these committees, in turn, to use participatory learning and action (PLA) methodologies to mobilize community OVC committees. Most of the community OVC committees have started community schools for orphans and other children too poor to attend government schools. Other community OVC initiatives include intervening to protect abused children and successful group income-generating projects. The District OVC committees also provide a forum for information exchange and coordination among

The strongly felt concerns for their children are the driving and potentially sustaining force behind these initiatives by AIDS-affected communities. These concerns are not generated by the community mobilization process, but that process brings people together and produces a shift in perception from the needs of orphans being individual and family responsibilities to these being recognized as shared community issues that can be more effectively addressed through cooperative efforts. Because the motivation to participate comes from personal and community-recognized concerns, it is essential to recognize that communities must define for themselves which children and which threats to their current and future well-being they are most concerned about. This means that the outside agent cannot predetermine the specific activities or outputs that the process will generate, or even the issues that will be addressed.<sup>9</sup>

Each community that is mobilized can only be expected to address, on an ongoing basis, problems for which its members have assumed responsibility and to sustain activities that they, themselves, have decided upon. While some community groups have addressed the needs of orphans on their own initiative, it would be unrealistic to expect that all communities will eventually do this on their own.

Programs like FOCUS in Zimbabwe, COPE in Malawi, and the OVC program in Zambia are showing that it is possible to mobilize communities systematically, build their capacities, and help sustain their efforts over time with very limited amounts of support.

The specific kinds of capacity building that need to follow mobilization depend and build upon a community's existing capacities and its opportunities, resources, and commitments about how it can respond to the needs of vulnerable children. Capacity building may include training in program development and management; local resource mobilization and fundraising, proposal writing, or in such areas as child development, health care, nutrition, and children's rights under national law and the United Nations Convention on the Rights of the Child. It is an ongoing process that involves helping communities to use their own capacities and resources effectively, to identify and link with external resources; and to develop skills in assessment, decision making, planning, monitoring, and evaluation.

**The COPE program of Save the Children (US) in Malawi** has mobilized communities at health catchment area and village levels to respond to the needs of orphans and other vulnerable children. COPE staff work closely with government, church, business, and NGO personnel, and in communities they are viewed as being part of the district- or community-level AIDS committees rather than NGO service providers. Health catchment area AIDS committees mobilize action at the rural village level by bringing people together to assess their problems and concerns as a community. District and health catchment-level AIDS committees also do training, provide information, and facilitate access to external resources. They have linked village committees to agricultural extension agents who provide advice for communal gardens that produce food and income to benefit vulnerable households. Village AIDS committees raise funds to assist especially vulnerable children, organize youth anti-AIDS clubs that conduct prevention education and provide support to vulnerable households, intervene with schools and guardians to enable orphans to return to

## **Microfinance Services**

Many of the problems of AIDS-affected children and households result from their economic problems, as Figure 1 indicates, so it is fundamentally important to establish in their communities sustainable interventions that respond effectively to household economic needs. State-of-the-art microfinance programs show good potential for increasing economic resilience among poor households in a sustainable, cost-effective manner.

Solidarity group lending (also known as village banking) is perhaps the best known methodology of such programs. Typically, this methodology includes a body that makes loans to self-selected groups, the majority of whom are often women. Individual group members each use their share as they choose, usually for individual or family-based income-generating activities, and each is responsible for repaying the group with interest. The group, in turn, repays its collective loan, with interest, to the loan body, often through weekly or biweekly payments over a few months. Such programs generally have rules requiring individual and group saving requirements to help ensure loan repayment, and interest rates are set at or above the market rate, high enough to cover the operating costs of the body making the loan. In state-of-the-art microfinance programs, repayments rates are well above 90 percent and sufficient to sustain a program's operation as an independent financial institution. Globally, at least 22 million women and men are accessing microcredit from 925 institutions.

Many agencies implementing microfinance programs limit their services to women. Research has shown that in most cultures women are more likely than men to spend income that they control in ways that will immediately benefit their immediate family, such as for food, health care, and education.

While microfinance services are very promising as a way to strengthen family and community economic capacities, it is necessary to raise some points of caution. Where microfinance programs have become sustainable, they have done so by adhering closely to tried and true operational practices and respecting the economic realities and constraints of the situation in which they work. Successful programs are delivering services in communities seriously affected by HIV/AIDS, but initiatives have floundered when they have attempted to target loans to groups selected by an agency, such as households affected by AIDS. Groups must be self-selected. If an agency tries to engineer the composition of loan groups, it typically undermines the solidarity and mutual confidence among group members and can concentrate too much risk of business failure within a single group.

A second caution is that successful microfinance programs require specialized expertise. Health or social welfare personnel are not likely to be effective microfinance managers. Also, it would be very difficult for an organization whose purpose is to make social welfare or health service interventions to be effective in managing a sustainable microfinance program. The clash of objectives would likely be too great within a single program. It would be very difficult at the community level, on the one hand, advocating a compassionate response to those in need while,

on the other hand, being uncompromising about timely and full loan repayments. However, operationally separate community mobilization and microfinance programs can coordinate effectively and find ways to reinforce each other's effectiveness.

In communities seriously affected by AIDS, microfinance services should not be seen as an intervention that is going to pull destitute households out of poverty. However, credit, and savings services smooth out income flow, increase food security, and help cover school and health expenses in poor households which are capable of engaging in income generating activities. The Foundation for International Community Assistance (FINCA), for example, established a solidarity group lending program in Uganda, initially using funds from USAID intended to benefit orphans. This program is growing (650 village banks with 19,500 members in 1999, each representing a different household) and maintaining loan repayment rates above 98 percent. When members of these village banks were asked, three-quarters reported that they were caring for orphans. FINCA is also achieving similar success in communities affected by HIV/AIDS in Malawi. In a comparable program, a 1999 evaluation of the Uganda Women's Finance Trust (UWFT) found that it had reduced the vulnerability of poor individuals and households, many of whom were affected by HIV/AIDS.

### **Other Development Interventions**

Interventions to mitigate the impacts of HIV/AIDS must be tailored to the particular economic, social, cultural, and environmental contexts of the countries and communities concerned. There is no one-size-fits-all approach. For example, one of the recommendations of our team assessment in Uganda in 1991 was to upgrade feeder roads in areas devastated by AIDS. Roads had badly deteriorated over the country's years of misrule and civil war. The staple plantain sold in a city market for ten times the price it would bring in a more remote village because of the difficulties with transportation and the related breakdown in agricultural marketing systems. In that context, upgrading feeder roads was one of the measures that offered good possibilities for improving the economic situation of the communities struggling to care for orphans. In other situations, subsidizing key agricultural inputs or tools, establishing new market links, or a variety of other development interventions might be cost-effective ways of improving the economic situation of families and communities.

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. The history of "development" however, is full of examples of interventions that did not work or of interventions that made matters worse. I offer three basic guidelines for identifying measures that are more likely to produce beneficial results. The first concerns the process: the people expected to benefit need to be actively involved in the process of deciding what kind of intervention would help and how it should be implemented. They should also have active roles in monitoring, evaluating, and adjusting interventions. This means that bodies who would intervene (government ministries, NGOs, religious bodies, international development agencies, etc.) should

ensure that the process of assessment, planning, implementation, and evaluation is designed to promote and reinforce community ownership of the problem and a sense of responsibility for taking action.

A second consideration concerns the substance of what is to be done: economic activities with which intended beneficiaries already have some experience and expertise generally stand a much better chance of success than new ones introduced from the outside. It is usually more effective to build upon what people already know than to introduce radically new technologies, crops, or activities.

A third important area to consider is how a possible intervention will involve and affect women. In most countries women carry the major share of the burden of caring for those who are ill and for orphans, in addition to most household tasks and many key economic activities. Development interventions that women identify as being important to them 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 time for economic activities, or planting fast-growing tree varieties to reduce the time and effort needed to gather firewood. On the policy side, strengthening and protecting the rights of widows to own land and to inherit property would be important development interventions.

## **Education**

Paying school expenses can be a prohibitive financial burden for families affected by HIV/AIDS, and girls, on whom much of a community's future well-being will depend, are often forced to drop out before boys. Government fees are typically a small part of the expenses families face to send a child to school. Many schools are able to function only by charging their own fees, which can be substantial. Other expenses include uniforms, books, and supplies. The additional expenses and loss of cash income or agricultural labor that come with illness force families to redirect their financial resources. Children are often forced to drop out of school before they are orphaned, and school expenses may no longer be affordable when children have to leave school to care for ailing parents and take on adult work responsibilities.

Death of teachers due to HIV/AIDS is another serious problem many governments are facing in maintaining the quality and availability of education. In Zambia, for example, the mortality rate of teachers in Zambian schools is 4 percent per year, and between four and five teachers die each day.<sup>10</sup> While not all of these deaths are caused by AIDS, the epidemic is the likely explanation of why the teachers' death rate is significantly higher than that of the adult population in general. A recent report indicated that in Swaziland, a smaller country than Zambia, three to four teachers are dying per day. In 1993, it was estimated that, due to HIV/AIDS, Swaziland would spend almost one and a half million U.S. dollars in 1996 to replace and retrain teachers.<sup>11</sup>

A recent controlled study on the situation of children orphaned by HIV/AIDS carried out in four districts in western Kenya found that children, one or both of whose parents had died of HIV/AIDS, were significantly disadvantaged compared to other children. The study included 646 children, one or both of whose parents had died of HIV/AIDS, and a matched control group of 1,239 children. Among children in the control group, 73 percent had both parents living and 27 percent had lost one or both parents from causes other than the epidemic. The study also found that 52 percent of the children orphaned by HIV/AIDS were not in school, compared to two percent of the control group. Among the children orphaned by HIV/AIDS, 56 percent of the girls and 47 percent of the boys were not in school. Also, school performance and health were poorer among the children orphaned by HIV/AIDS.<sup>12</sup>

From national to community levels, there have been a variety of responses made to help orphans and other vulnerable children stay in school, but there are no easy answers to the resource deficits HIV/AIDS is causing. Providing scholarships is a direct and efficient solution, but the expense makes it difficult to sustain this activity as an escalating number of children drop out of school. Some ministries of education have waived school fees for orphans, which can help, but the resulting deficits in ministry and school budgets have to be made up from other sources.

Some organizations have provided supplies and equipment or constructed classrooms for schools prepared to accept orphans. Community schools are another approach. Some communities have started community schools to provide educational opportunities for children unable to afford the costs associated with regular schools. Such schools are less expensive per pupil than government schools, but communities face significant challenges to support them indefinitely.<sup>13</sup>

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 children return to school by persuading their guardians that these children need to be in school. Appeals by local religious groups, emphasis on traditional values and responsibilities, parenting skills classes, and sensitization to children's rights can 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. A recent evaluation of the UWFT, a microfinance program, found that participants used income secured through the program to pay both educational and health expenses, "It is interesting and important to note that UWFT's services are allowing clients to make substantial investments in sending children to school and curative health care. Indeed, these (and particularly education) repeatedly emerge as the most valued results of access to credit."<sup>14</sup>

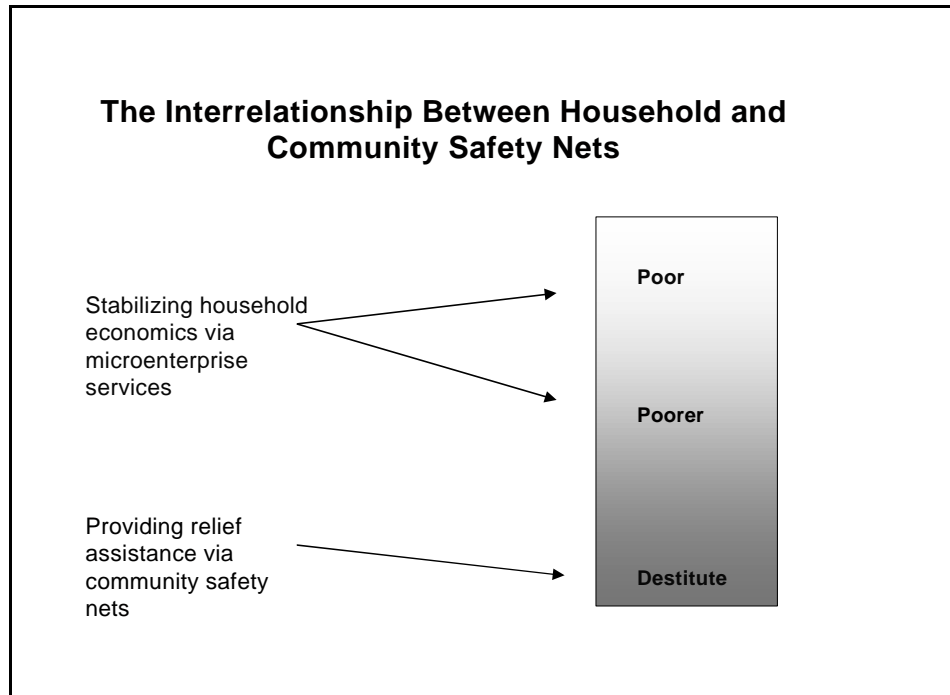
## **Sustainable Relief**

Measures to strengthen both family and community safety nets are needed to generate and sustain effective responses to the impacts of HIV/AIDS. Neither community mobilization, microfinance services, nor other development interventions, in isolation, would yield sufficient responses to



the various degrees of vulnerability HIV/AIDS causes among children and families. The economic stress HIV/AIDS causes in some families is so severe that income generation is not an immediate option for them. They need a safety net, and the community, with some outside support, is in the best position to provide it. Material relief and moral support furnished by friends and neighbors can help ensure survival, but community-based relief assistance is not likely to be sustainable in the long term without economic reinforcement. Over time, weakened households must regain their capacity to cope by depending on their own resources.

**Figure 3. The Interrelationship Between Household and Community Safety Nets**



Sustaining the capacity of families and communities to cope with the impacts of HIV/AIDS requires ongoing interaction between community mobilization and capacity-building interventions and others that build household and community economic resources. In the context of community-based responses to mitigate the impacts of HIV/AIDS, it is necessary to consider the economic stability of the entire community. If too many families slide into destitution, the community safety net will be overwhelmed because there will be too few people to share its resources. Effective microeconomic interventions that help stabilize household incomes can reduce the number of households sliding into destitution and increase the ability of poor and less-poor households to continue helping those who are even more vulnerable than themselves. Microfinance and other appropriate development interventions can help strengthen households so they can weather the storm if they are seriously weakened by HIV/AIDS, as well as enable them to be better able to provide emergency support to more vulnerable neighbors.<sup>15</sup>

## Why Institutional Care Is Not the Answer

As a strategy to respond to the growing number of children orphaned by HIV/AIDS, providing more places in residential institutions is an expensive way to increase the problem. In communities under economic stress, the more places that become available in institutions, the more children are likely to be pushed out of poor households to fill them. In many parts of the world, very poor families have often used “orphanages” as an economic coping strategy and a way to secure for their children access to services or better material conditions.

More importantly, child development specialists have recognized for decades that institutional care generally fails to meet many of children’s developmental needs, such as those for attachment, social integration, and acculturation. It has long been recognized that whether these needs are met or not has important long-term implications for children and the adults they will become. When writing about the importance of family care for children during the Second World War, Anna Freud and Dorothy Burlingham wrote

The war acquires comparatively little significance for children so long as it only threatens their lives, disturbs their material comfort or cuts their food rations. It becomes enormously significant the moment it breaks up family life and uproots the first emotional attachments of the child within the family group.<sup>16</sup>

In a similar vein, a 1994 study done for the Department of Social Welfare in Zimbabwe on child welfare policy and practice concluded

The potential for an inappropriate response to the orphan crisis may occur in the Zimbabwean situation, where a number of organizations are considering building new institutions in the absence of any official and enforced policy relating to orphan care.... There is a danger in looking only at the physical and educational needs of children. To families struggling to cope with orphans in their care, a Children’s Home naturally appeals because the child is guaranteed food, clothing and an education. However, this study demonstrated that the various models of institutional care fail to fully meet the emotional and psychological needs of children and adolescents.... There is no substitute for care of the child within his/her family of origin. Programmes to keep children with the community, surrounded by leaders and peers they know and love, are ultimately less costly, both in terms of finance and the emotional cost to the child. In many instances, admission to placement could be avoided by targeting vulnerable families and providing financial assistance such as school fees to parents or relatives.<sup>17</sup>

Institutional care has largely been abandoned in the developed countries, but survives as a cultural import in the developing world, where the extended family and community are the traditional mechanisms for ensuring the care of orphaned children. Generally, family-based care meets children’s developmental needs better, and this is why families have evolved as the principal structure for raising children.

Placement in residential institutions is best reserved as a last resort for the care of vulnerable

children—it is best used as a temporary measure until a family placement can be arranged, and for some children, it may be the only alternative to the street. David Tolfree’s groundbreaking book, *Roofs and Roots: The Care of Separated Children in the Developing World*, emphasizes the need for preventing family separation, the shortcomings of residential care, alternatives to it, and ways to improve residential care where it does exist.<sup>18</sup>

Institutions in the developing world often serve more as an economic coping mechanism for very poor families than as a child protection measure for children without other options. For example, in Uganda, a 1992 survey found that approximately 2,900 children were living in institutions. This was in the wake of both years of armed conflict as well as increasing deaths from HIV/AIDS. The survey also found that about half of the children had both parents living, 20 percent had one parent alive, and another 25 percent had living relatives. Poverty was the reason these children were in residential care. Guided by the survey findings, a multi-year effort by the Ministry of Labor and Social Affairs and Save the Children (UK) improved and enforced national policies on institutional care, reunited at least 1,200 children with their parents or relatives, and closed a number of sub-standard institutions.<sup>19</sup>

The cost of supporting a child to live in an institution is substantially higher than that of supporting care by a family. The World Bank reported that the annual cost for one child in residential care in the Kagera region of Tanzania was over US\$1,000, almost six times the cost of supporting a child in a foster home.<sup>20</sup> Even if institutionalization were a good option for children, the resources will not be available to sustain a large number of children in institutions at anything approaching a decent standard of care, and institutions will consume resources that could produce greater impacts through community-based efforts.

Extended family care is sometimes ruled out too quickly by NGOs wanting to assist orphans and children at risk of losing their parents. For example, one program working in Nairobi’s slums found that when 200 single mothers who were HIV positive were asked who could care for their children if they became too ill to do so, half denied having any extended family members who could possibly provide care. The social worker who interviewed the women found, however, after developing a relationship with them, that almost all did have relatives from whom they had become estranged, and she was able in almost all cases to identify a grandmother or other extended family member prepared to provide ongoing care for the children when their mothers became too sick to do so. It is significant that their willingness to accept the children was not contingent upon provision of cash or material assistance.<sup>21</sup>

Too often institutional care is seen as the only alternative in situations where care within a child’s extended family is not a good option. There are, however, other alternatives to consider. One is actively involving leaders and community residents in establishing one or more small group homes within children’s own communities. This can be done with the ongoing support of a religious body, NGO, or community-based organization. Also, in some cases a group of siblings may decide to remain in their home after the death of both parents. With adequate support from the extended family or community members, this can be an acceptable solution because it

enables the children to maintain their closest remaining relationships. In rural areas, it may also enable them to retain the use of their parents' land. Such options are more likely to be viable in communities that have been sensitized and mobilized around the needs of vulnerable children or where members share strong religious or other ties.

## **Scaling Up Sustainable Responses**

Because the number of children orphaned by HIV/AIDS can be expected to increase and remain high for another two or three decades, sustainability and scale are key challenges that interventions must satisfy, even in the countries whose epidemics are already advanced. This is not to say that each program must cover the whole country, or even a large part of it. But collectively they must do so, and available resources must be shared effectively among them. In the countries most severely affected by HIV/AIDS, no single body—governmental, international, or nongovernmental—has the capacity to unilaterally address effectively the whole range of needs and problems among the vulnerable children. Each must play a part in a collaborative effort to mitigate the impacts on children and families.

## **Cost-Effectiveness**

One implication of the need to identify, scale up, and sustain effective interventions is that much more attention must be given to the cost-effectiveness of interventions. It is essential to develop measures that, with limited resources, can significantly improve the situation of AIDS-affected children and do so on the same scale as the epidemic is making them vulnerable.

The strategic importance of cost per beneficiary was highlighted during a 1996 program assessment in Malawi. The program's activities were all relevant to the problems of AIDS-affected children and families. It addressed health, education, training, and psychosocial needs of children, provided training in home-based care, supported gardening and other income-generating activities, and included a microfinance component. Its staff considered the program to be community based because many of its activities were being carried out by community volunteers. It became evident during our 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 lead to the collapse of the activities that had been started in the initial area of operation. Further, the cost per beneficiary was calculated to be approximately US\$162. Our team calculated that reaching even 10 percent of the estimated 500,000-750,000 orphans in the country would cost US\$8 to 12 million per year. It was clear that it would not be possible to secure and sustain indefinitely anything approaching this level of funding for one country of modest population, even with the collaboration of multiple donors, because countries throughout the region were facing similar problems, and the number of orphans was continually increasing.

Although funding to address problems among children and families affected by HIV/AIDS is increasing as the magnitude of the situation and the reversal of development gains become more apparent, it cannot be expected that hundreds of millions of aid dollars will be available each year to establish and sustain national social welfare relief programs in all the developing countries seriously affected by HIV/AIDS. It would be foolish to wait for aid in the hope that such funding will materialize. The only realistic option is for agencies and groups to pull together a collective set of responses, including grassroots initiatives, larger NGO-supported programs, faith community networks and programs, and national-scale development initiatives and policies. At each level of society, from the village to the nation, concerned individuals, groups, and agencies must come together, assess needs and capacities, and find ways to collaborate to secure the protection and care of the most vulnerable children. There is no viable alternative to this strategy, and there is no blueprint for how to do it. Each country and community must look at its own situation and build its own set of responses, and leadership is needed at every level to make this happen.

## **Structures for Collaboration**

Developing effective collaborative action requires the use of existing coordination structures and, as necessary, the development of new ones. Key actors in each country must look at their own situation and determine what will work best in that context. Such networks for information sharing and collaboration need to take account of what programs and policies exist, which are working well, and which are not. To be effective, a national-level coordinating structure needs to link with the many agencies and networks that exist and have influence and impacts at the community level. The result may resemble a patchwork quilt that is continually being revised and repaired more than it does a uniform organizational structure. The issue will be whether the various bodies manage collectively to make a positive difference in the lives of the most vulnerable children and families.

Malawi is one country that has attempted to develop a uniform structure to address HIV/AIDS and its impacts, with mixed success. The country has an interagency national orphans task force chaired by the government with NGOs and international organizations taking part. In 1994, the government, with the assistance of UNICEF, developed a standard, country-wide structure of AIDS committees. It was decided that at national, district, community (health catchment area) and village levels throughout the country AIDS committees would be formed involving government personnel, NGOs, religious groups, private-sector and other interested participants. Each of the AIDS committees from the district level down was to have four technical subcommittees: high risk (prevention), home-based care, youth, and orphans. In practice, very few resources were provided to implement this mandate, and the results were mixed, with little happening below the district level. In some areas, however, organizations have provided resources and revitalized this structure to mobilize action at health catchment and village levels.

## Targeting

Scaling up interventions requires targeting resources in ways that make a difference to the most vulnerable children and families. Even if cost-effective responses to the most critical needs of vulnerable children and families are developed, sufficient resources are not likely to be available for them to be uniformly implemented throughout a country.

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, broken down to a district or similar-sized administrative level, that indicates the prevalence of problems. Depending on what information is available and reliable, this might include rates of orphaning, adult mortality, infant mortality, malnutrition, school dropouts, income levels, and/or other poverty measures. Rates of double orphaning (children both of whose parents have died) can be used to identify areas where AIDS is more advanced. A census or major health survey is a good opportunity to include questions to generate useful indicators. The first stage of targeting also includes mapping the availability of key services to address such questions as: Where are interventions already being made; how adequate are these interventions; and where is the mismatch greatest between problems and existing services?

Such data must also be tested through assessments on the ground and consultation with people in the communities where problems appear to be greatest. This kind of participation should be a key part of any situation analysis.

The second stage of targeting depends even more heavily on people in the most affected areas. They 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 likely to be able to make their needs known, and residents are generally much better able than outsiders to determine what factors indicate serious vulnerability and to 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,
- Health problems,
- Quality and frequency of meals,
- Economic activity lost,
- Economic activity of a surviving parent,
- Household size,

- Access to arable land,
- Loss of home or possessions, and
- Separation of siblings.

## **Monitoring, Evaluation, and Research**

The unprecedented nature and impacts of the HIV/AIDS pandemic necessitate ongoing monitoring of 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, they must include mechanisms to measure their impacts, which, in turn, provide a basis for adjusting interventions to make them more effective. These mechanisms should include participatory appraisal methods that community residents can use to measure impacts of HIV/AIDS and the effectiveness of responses.

In addition, it is valuable to identify within a country those NGO, university, and private-sector groups that can be called upon to undertake short-term, operational research and produce quick, practical, easy-to-understand reports on specific issues. Examples of possible strategic monitoring and research issues include the following:

- Development of child and community vulnerability indices to use in mapping and setting geographic priorities for interventions;
- Identification of which processes, approaches, and models are more effective in urban, peri-urban, or rural communities and in different farming systems;
- Ways that care activities, especially those involving children and youth, can contribute to HIV prevention; and
- Impacts of HIV/AIDS on family and community economic coping strategies.

## **Integrating Care and Prevention**

To increase the effectiveness and efficiency of interventions, those engaged with HIV/AIDS issues must give greater attention to ways that care and prevention activities can reinforce each other. For example, there is growing interest in ways that orphans activities and other kinds of care can provide entry points for promoting HIV prevention at the community level. Care issues are concrete and of immediate concern. Making changes in personal behavior to avoid HIV infection, on the other hand, requires a series of conceptual leaps, such as a firm belief in germ theory, a strong future orientation, and a conviction that what one does now will make a significant difference in the distant future. This makes effective HIV prevention a very difficult enterprise, so it is worth assessing carefully whether people's immediate engagement with the concrete realities of care issues can be a catalyst for prevention efforts. Prevention should be approached in ways that make sense in terms of people's day-to-day experiences and concerns.

One of the main reasons why HIV has spread as extensively and rapidly as it has is the long lag between infection and illness. The link between change in sexual behavior and avoidance of illness is more difficult to demonstrate, for example, than the reduction in malaria and the use of treated bed nets. It may be that engagement in care activities can help make a cause and effect link in participant experience that will reinforce prevention messages. Also, the sense of empowerment that comes through community mobilization—joining with others to address immediate problems—may stimulate a sense of hope and the belief that it is possible to have greater control over the things that affect our lives. Hope and empowerment may increase receptivity to prevention messages.

Linking care and prevention activities seems particularly relevant in programs involving children and adolescents. In many countries, young people frequently show a willingness and capacity to organize and address community problems. For example, in addition to providing direct benefits for those assisted, promoting the engagement of youth anti-AIDS clubs in the emotional support and daily living needs of orphans or people living with AIDS can provide opportunities to convey and reinforce prevention messages among participating youths. As one agency head from Zambia observed, anti-AIDS club members get bored if they just talk about why they should not be having sex.

Care interventions should be integrated in ways that help AIDS-affected households cope with the range of problems they are facing, including caring for people who are ill, gaining access to basic medications, reducing stigma and psychosocial distress, keeping children in school, and compensating for lost adult labor and income. The care and support of people living with AIDS should be linked with efforts to mitigate the economic impacts on their families. The psychosocial needs of parents living with HIV/AIDS and their children are directly related and can be addressed through integrated interventions.

### **Building Political, Public, and Donor Support**

After years of denial and avoidance on the part of policy makers, community leaders, organizations, donors, and the public, it has become imperative to build widespread recognition of the impacts of HIV/AIDS on children and families and to stimulate appropriate action. Increased awareness by itself may generate 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, and it must convey a clear vision of how to do it. A participatory situation analysis can be the first step in motivating key figures to recognize and engage with the issue, and it can also provide much of the information needed for broader social mobilization. Priority attention should be given to those who can amplify and transmit key messages, such as government leaders, representatives of the media, religious leaders, and popular sports and entertainment figures. 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 can still be done to make a difference.



A broadly inclusive national conference can provide a good opportunity to present the findings and recommendations of a situation analysis. Such an event can be used to raise awareness among key actors and, through media coverage, among the public at large. Involving senior government officials and key leaders in the event and ensuring they are briefed on the findings of the study beforehand enables them to draw attention to emerging problems and can help attract participants and media attention. A central message of such a conference would be that HIV/AIDS is not just a health issue, but a slowly emerging disaster causing broad and serious social impacts as well as profound individual tragedies. Beyond increasing the visibility of problems, a conference can help lay groundwork for an enabling environment through the following means:

- Initiating discussion of how to interpret and use situation analysis findings;
- Pushing ministries and organizations not yet involved to define roles they can play;
- Identifying potential resources;
- Drawing attention to the need for ongoing information sharing and coordination;
- Generating support for a strategy to strengthen the capacity of affected children, families, and communities; and
- Promoting support for specific recommendations.

Religious bodies, civic organizations, and other NGOs can play important roles in raising awareness and promoting community support for those affected by HIV/AIDS. In many countries, religious networks are more extensive than those of the government, and they can be influential in promoting a compassionate response to people living with AIDS. Also, families can play critical roles in identifying the most vulnerable persons among those affected and help mobilize community responses to their needs.

Influencing public attitudes about the situation of those affected by AIDS calls for the active involvement of the communications media. A good way to start this process would be taking selected journalists to visit willing households and children affected by HIV/AIDS and providing them with background information on the national scope of HIV/AIDS-related problems. Another step could be to involve journalists in an informal dialogue about how to increase public awareness of the epidemic's effects and mobilize action. UNICEF or other international organizations may be able to provide professional expertise for planning a media campaign. Videos, such as *Everyone's Child* and *The Orphan Generation* can be useful tools in promoting understanding of the issues and motivating action.<sup>22</sup>

Families and communities are the front line of response to HIV/AIDS, but they are not going to be able to win the fight alone. They need support from a broad range of agencies, organizations, and individuals at each level of society. Intensive efforts are also needed to ensure the protection and care of children who slip through the primary safety nets of family and community. Each of us must recognize the urgency of these tasks and do what we can. HIV/AIDS is already seriously

undermining the survival, well-being, and development of millions of children, and concerted action is needed now.

## Notes

1. Susan Hunter and John Williamson, "Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS," prepared by the Health Technical Services Project for the United States Agency for International Development, December 1997, fig. A-4.
2. *Ibid*
3. Choolwe G. Mudenda, Solomon Tembor, and Frank Kakungu, "The Situation Analysis of Orphans in Zambia: Data review and enumeration," draft report, 1999, p. 3 and Hunter, *op. cit.*
4. "AIDS epidemic update: December 1998," UNAIDS and The World Health Organization, p. 3.
5. "AIDS Africa's Real Killing Field," the Associated Press, Richmond Times-Dispatch, Richmond Virginia, USA, September 16, 1999, p. A5.
6. *Report on the Global HIV/AIDS Epidemic*, June 1998, UNAIDS.
7. WHO and UNICEF, New York, December 1994.
8. See for example: <http://www.dec.org/> and [http://www.info.usaid.gov/about/part\\_devel/docs.html#partpract](http://www.info.usaid.gov/about/part_devel/docs.html#partpract)
9. See Jill Donahue and John Williamson, "Community Mobilization to Mitigate the Impacts of HIV/AIDS," Displaced Children and Orphans Fund of USAID, September 1, 1999.
10. Presentation by Professor Michael Kelly at the September 1999 International Conference on AIDS/STDs in Africa in Lusaka, Zambia, reported by AF-AIDS listserve.
11. Susan Hunter, "Sectoral Assessment of the Impact of HIV/AIDS on Education: Initial Planning Guide," draft report prepared for the Ministry of Education, the Kingdom of Swaziland, 17 April 1999.
12. Notes from a presentation by Dr. Michael Elmore-Meegan at the Collaborative Symposium on AIDS, January 1999, Nairobi, Kenya on research by ICROSS for which publication is pending.
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14. Graham A.N. Wright, et al., "Vulnerability, risks, assets and empowerment--The impact of microfinance on poverty alleviation," prepared for the World Development Report 2001, March 1999, p. 111.
15. Jill Donahue, "Supplementary Report," prepared as a supplement to the report, "Children Affected by HIV/AIDS in Kenya: An Overview of Issues and Action to Strengthen Community Care and Support," a joint report by USAID's Displaced Children and Orphans Fund and UNICEF, August 1999, p. 9 and John Williamson and Jill Donahue, "Community Mobilization to Address the Impacts of AIDS: A Review of the COPE II Program in Malawi, January 17-30, 1998," prepared by the Displaced Children and Orphans Fund and War Victims Fund Project for USAID, June 1998, pp. 14-16.
16. *War and Children*, New York: Medical War Books, 1943, p. 67, as quoted in Everett Ressler, Joanne Marie Tortorici and Alex Marcelino, *Children in War: A Guide to the Provision of Services: A study for UNICEF*, New York, 1993, p. 181.
17. G.M. Powell, S. Morreira, C. Rudd, P.P. Ngonyama, "Child Welfare Policy and Practice in Zimbabwe," pp. 36 & 37.

18. Arena, Ashgate Publishing, Harts, England, and Brookfield, Vermont, USA, Save the Children Fund (UK), 1995.
19. John Williamson, Adugna, S. and Jones, C., "USAID Assistance for Ugandan Orphans: A Mid-term Evaluation," Atlantic Resources/USAID, March 1994, p. 48; "Final Report of the Program for the Better Protection of Children in Uganda," Save the Children (UK), p. 14, and personal communication.
20. *Confronting AIDS: Public Priorities in a Global Epidemic*, The World Bank, Oxford University press, 1997, p. 221.
21. Interview with Father Edward Phillips, Chair, Eastern Deanery Community-Based Health Care and AIDS Relief Program, Nairobi, March 8, 1999.
22. *Everyone's Child* was produced by Media for Development Trust, Harare, Zimbabwe, and is distributed by DSR (dsr@us.net). The Orphan Generation was produced by Small World Productions. It can be ordered through the UNICEF web site: <http://www.unicef.org> Click on catalogues and follow the instructions regarding ordering forms. *The Orphan Generation* is not listed on the web site, but the title can be filled in on the order form.