

**Understanding Community Responses to the Situation
of Children Affected by AIDS:
Lessons for External Agencies**

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Throughout Africa, the AIDS epidemic is affecting large numbers of children and generating serious psychological, social and economic problems. Many children who are not themselves infected suffer the consequences of prolonged parental illness. Many others have already experienced the loss of their mother, their father, or both. Estimates for 26 African countries suggest that the number of children losing one or both parents will more than double between 1990 and 2010. By the latter year, 15 percent of children in these countries will have lost one or both parents, with the figure rising as high as 37 percent in Botswana, 34 percent in Zimbabwe, 32 percent in Swaziland and Namibia, and 31 percent in South Africa and Central African Republic (Hunter & Williamson, 2001). During the same period, those who have lost *both* mother and father will increase eight-fold overall in Africa (from 1.5 to 12 million), with a staggering seventeen-fold increase (from 0.2 to 3.4 million) in southern Africa. Even if rates of new HIV infections in adults were to fall in the next few years, the long incubation period would mean parental mortality rates would not plateau until 2020. The proportion of orphaned children (losing either one or both parents) would therefore remain unusually high throughout the first half of the twenty-first century.

Despite massive increases in orphan numbers, surprisingly small numbers of children have, up to now, slipped through the safety net provided by the extended family. In general, fostering is provided by relatives. Nevertheless family coping strategies are under enormous strain. It is thus important to understand the recent proliferation of initiatives supporting vulnerable children at the community level. These responses to the epidemic – growing out of community solidarity, compassion and religious belief – are often hardly known outside their immediate locale. They have been little studied or documented, and few external organizations have sought to foster their development. Yet robust community initiatives will be an essential element in caring for growing numbers of orphans and vulnerable children in coming years. They must form part of an expanded response to the tragedy of HIV/AIDS.

In the following pages, some of these initiatives will be analysed, with a view to encouraging appropriate support from external institutions ranging from local and national NGOs and researchers to international agencies. At the same time, the paper will attempt to discourage inappropriate support and to underscore the point that ill-advised assistance can easily undermine community initiatives. Outsiders can often play a more useful role as facilitators of community-based programmes than as direct service providers. They can build capacity, and increase the scope and scale of existing activities, without imposing externally-designed solutions that often have negative consequences.

The disastrous impact of AIDS on children²

Over twenty years have passed since the first deaths from AIDS; and during that time, scientific progress has been made on many fronts. Yet the impact of the epidemic on children and families has been particularly hard to analyze, and even harder to put on the agenda of policy makers, philanthropic agencies and political and scientific leaders (Foster, 1997). The primary focus of clinicians, researchers and service organizations has been on people who are ill and dying, and the first concern of public health officials has been to prevent HIV transmission. Children's issues have been seen mainly in the context of mother-to-child transmission and pediatric AIDS, certainly a compelling part—

²This section draws heavily from Levine & Foster, 2000

but only a part—of the picture. The relative indifference of national and international institutions has been a consequence of the chronic, diffuse impact of this disaster on uninfected but vulnerable children whose situations are barely seen and whose voices are hardly heard.

Children suffer from the social, economic and psychological consequences of the epidemic several years prior to death of a parent, as they live with prolonged or recurrent parental illness (Foster & Germann, 2001; Gilborn et al, 2001). And in fact, some studies suggest that the severity of the epidemic's impact on a child may be greater before he or she is orphaned than it is in later years. Most children show psychological reactions to parental illness and death such as depression, guilt, anger and fear. Furthermore, the recurrent impact of AIDS at the household level can be associated with continuous traumatic stress syndrome and a second generation of problems such as alcohol and drug abuse, severe depression, violent behavior and suicide (Straker, 1992).

The virulence of the epidemic also has significant consequences for some children who do not live in a domestic unit containing an affected parent. Extended families can be overburdened by the need to care for relatives suffering from AIDS. Better-off households may slip into poverty, and poor families can slide into destitution. This generalized decline in levels of living increases the vulnerability of children to a range of consequences including illiteracy, poverty, child labor, exploitation and unemployment. For this reason, reference will be made in the following pages both to orphans and to vulnerable children, including those with sick parents, the handicapped and the destitute.

The extended family safety net

African children live in both "households" and "families": and though often used inter-changeably, these terms have significantly different meanings. A *household* can be defined as a group of people, living together, who are usually economically interdependent. *Families* in traditional societies typically involve a much larger network of connections among people, enveloping the household in relationships that include multiple generations, extend over a wide geographical area and are based upon reciprocal rights and duties. The term "extended family" places special emphasis on the role of relatives outside the household in providing economic and social support to survivors from AIDS-affected homes.

The extended family has been – and still is – the traditional social security system. Its members have been responsible for the protection of the vulnerable, the care of the poor and sick, and the transmission of social values. When relatives die, the extended family support network ensures that children are cared for -- whether some of its members move into households to care for survivors, or whether orphans are moved out into one or more relatives' households. In the past – and still to a considerable extent today – the sense of duty and responsibility of African extended families has been almost without limits. Even though a family may not have sufficient resources to care for existing members, orphans are taken in. This has been the basis for the assertion that, traditionally, "there is no such thing as an orphan in Africa" (Foster, 2000a).

The usual pattern of family obligation to care for orphans in sub-Saharan Africa can be envisaged as follows:

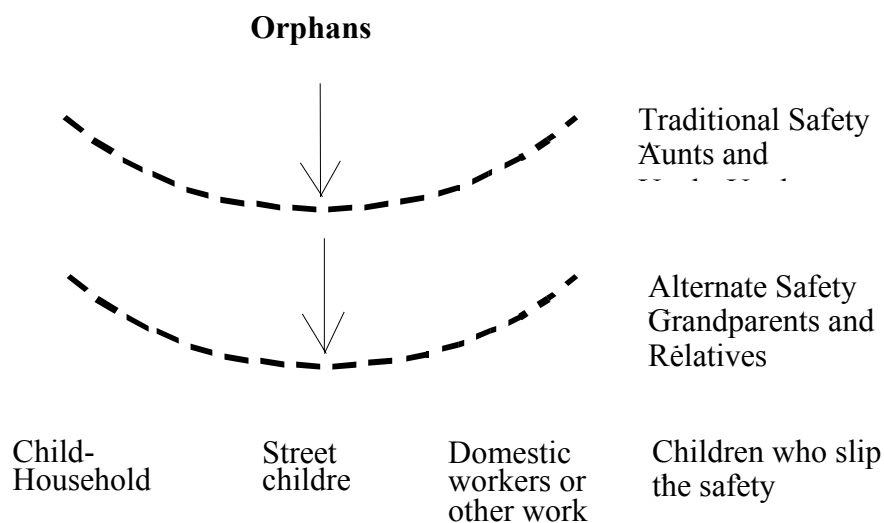


Figure: Model of the extended family safety net for orphans in Africa.

The first line of defense for a vulnerable child is formed by uncles and aunts. But as this customary practice of orphan inheritance has weakened, it has been supplemented by greater responsibility on the part of grandparents or other relatives – almost always women.

In recent years, changes such as labor migration, the generalization of a cash economy, demographic change, formal education and urbanization have weakened extended families. Structural adjustment policies that involve the imposition of cost recovery mechanisms for basic education and health services have also reduced the willingness of relatives to care for orphans and increased the likelihood that foster children will engage in child labor in return for their keep. Therefore some children slip through the extended family safety net and end up in especially vulnerable situations. Child-headed households, in particular, are a new form of coping established as a result of saturation of the extended family's capacity to care. Nevertheless, although the safety net may have failed to some degree, it still continues to function, even where children must live in vulnerable situations. Most children living alone still continue to receive some degree of support from their extended families (Foster et al, 1997a).

Thus, despite its weakening, the extended family remains the predominant caring unit for African children who have lost parents to the epidemic (Ankrah, 1993; Foster et al, 1995; Ntozi, 1997a). Given the scale of the AIDS epidemic in Africa, it is in fact remarkable that so few children are slipping through the safety net and ending up in vulnerable situations. No firm figures are available, but the total proportion of children in these situations probably represents less than two to three percent of all orphans, even in the most severely affected countries³. If an epidemic of African intensity were to

³ Estimates for children in these categories vary because of the lack of community-based surveys, standardized definitions of street children and working children, and because some agencies inflate numbers for promotional purposes. In Uganda, the prevalence of child-headed household was 0.03 percent, 0.4 percent and 3 percent in Mwanza, Tanzania, Mutare, Zimbabwe and Rakai, respectively (Foster et al, 1997; Nalugoda et al, 1997; Urassa et al, 1997). In a community-based survey from two districts in Uganda, none of the 233 households where orphaned children had been taken in was headed by a child (Gilborn et al, 2001). The street child population in Zambia is estimated at 75,000 with around 5,000 children who are homeless. The remainder live with relatives or friends (USAID / UNICEF / SIDA / Study Fund Project., 1999b).

occur on other continents, the number of children living on the streets, being exploited through child labor or fending for themselves at home would almost certainly be higher. Extraordinarily, the evidence up to now is that customary fostering systems in Africa will continue to meet most basic needs for a majority of orphans created by the AIDS epidemic, provided that their coping mechanisms are not undermined.

Nevertheless it is unfortunately true that the largest increases in orphan numbers are occurring in countries in southern Africa with higher rates of urbanization and weakened extended family safety nets. And, paradoxically, the undoubted effectiveness of the African extended family in absorbing millions of vulnerable children is contributing to the complacency of external agencies concerning the worsening condition of very large numbers of children affected by the epidemic.

International responses

Descriptions of the impact of AIDS on families and children in Africa started to appear in conference presentations and agency reports in the late 1980's.⁴ Academic articles estimating the future scale of the orphan epidemic and describing experiences in establishing a community-based assistance program were also published (Bos, 1991; Chin, 1990; Hunter, 1990; Preble, 1990). UNICEF and WHO were instrumental in disseminating research, conference proceedings and reports documenting the problem, analysing responses and proposing remedies (UNICEF, 1990; UNICEF, 1991; WHO, 1990; WHO & UNICEF, 1994).

However, through the 1990's, these early studies did not lead to concerted international responses, and the problem of children affected by AIDS was in general afforded low priority by the international community. For example, until Durban 2000, the topic of orphans did not appear on the formal agenda of International AIDS Conferences, although the growing problem was the subject of poster exhibitions. The programmes of these meetings were dominated by the bio-medical and pharmaceutical concerns of industrialized countries. At the same time, however, the situation of vulnerable children did become a dominant theme in international conferences devoted specifically to AIDS in Africa, with numerous presentations by African delegates on the situation of children and descriptions of programmes supporting orphans.

Throughout this period, international donors were relatively generous in their provision of assistance for AIDS interventions; but prevention, especially medically-oriented interventions such as blood screening, condom provision, management of sexually transmitted infections and establishment of testing centers, received the lion's share of international attention and funding. Care and support at the household and community level was granted limited attention, in part because constraints imposed by the "project" approach to development made it difficult for external agencies to support activities at the local level and in part because inadequate information was available. Knowledge about the situation of children affected by AIDS in Africa requires the accumulation of detailed anthropological data and other forms of social research that were not forthcoming. It was left largely to NGOs to experiment with programme development in this area, and to a small number of local researchers to study and document issues surrounding children affected by AIDS⁵

⁴ This subject was a major topic of concern at the *Global Impact of AIDS* Conference in London in 1988, which included six papers discussing different aspects of the emerging issue. Other early reports included Ankras, 1989; Barnett & Blaikie, 1990; [Conant, 1988]; Hunter, 1989

⁵For reviews of research on orphans and related issues including epidemiological characteristics of children affected by HIV/AIDS, coping mechanisms, current knowledge of the impact of HIV on children, programmatic responses and areas where important gaps in knowledge exist, see Foster & Williamson (2000) and Foster & Germann (2001).

The situation changed in 1998, with the release of *Children on the Brink*, a report commissioned by the US Agency for International Development, which predicted that 40 million children in 23 developing countries would lose one or both parents by 2010 (Hunter & Williamson, 1998). On World AIDS Day that year, President Clinton singled out the impact of the AIDS epidemic on children for special mention and committed additional US funds for an expanded HIV/AIDS initiative. Other international agencies followed suit, as did the new breed of venture philanthropists; and from being a neglected niche, the issue of children affected by AIDS almost overnight became a priority of international development. Large amounts of money were made available to deal with the newly perceived problem and international agencies recruited staff and sought to build up expertise.

Why was the response of international agencies to the impact of AIDS on children so late in coming? There are a variety of possible explanations depending on the characteristics of different external agencies.⁶ Reasons such as the fragmented and incessant nature of the epidemic's impact, the emphasis on prevention rather than care and support, the low priority given to areas that are primarily social rather than medical and the limited ability of children to be heard have been alluded to above. Some early studies also cast doubt on whether, in view of poverty, it would be advisable to support specific programmes for children, rather than relying on general community development approaches (Nærland, 1993). The lack of any proven model of orphan support might also have inhibited international agency involvement, though, it has to be said, child development organizations might easily have been at the forefront of developing and replicating pilot programs.⁷ And in some cases, agencies seemed to be afraid that resources destined to orphans might simply be swallowed up in a bottomless pit of humanitarian relief.

Furthermore, the exact nature of the problem was difficult to determine. Was it that children were slipping through the extended family safety net? That children without parents were dropping out of school? That orphans had psychological problems? That the economic situation of orphaned children was particularly dire? Or was it a combination of all these issues, plus a myriad others? The problem is multifaceted and diffuse, affecting education, health, economics, child welfare and other areas that are the established concern of development agencies. Perceptions of the orphan problem are based on a surprisingly small number of cross-sectional studies, situation analyses and reports from anthropological research. The extent of the problem is unclear and the degree of importance attached to it by international agencies is largely the result of observation of trends and anticipation of the future impact of the epidemic. In order to devise interventions that help to mitigate the impact of AIDS on children, it is necessary to develop a convincing picture of the kinds of situations requiring priority attention. And here another problem emerges.

Situational versus contextual analysis

Situational analysis is a common approach to the analysis of socio-economic problems. In the context of children affected by AIDS, it is increasingly used to provide a broad picture of the location and needs of affected families and communities, as well as to map the services and safety nets available to them. Once this is accomplished, observers can determine where significant gaps exist (Hunter, 2000). Such analysis serves as the basis for strategic planning and program design. It is particularly

⁶For a review of barriers that prevented children affected by AIDS from being considered a priority by Canadian AIDS service and international development organizations, see Costigan & Waring, 1996 and Foster, 1997.

⁷Some international child development organizations have piloted innovative orphan support programs, especially in the late 1990's. The point is that such programs, even where successful, have not been disseminated and replicated widely, even within the same organization and in the same country.

useful for service delivery; and it stands behind many excellent and effective programs. But situational analysis, as carried out by many external organizations, is insufficient in areas that are complex, those that involve a high degree of community participation, or those that demand consideration of the cultural and religious views of beneficiaries and participants.

Gerard Salole has elegantly argued the case for agencies to go beyond situational analysis and to concentrate instead on *contextual analysis* in their work.⁸ Understanding the context of a problem is more difficult than understanding specific situations. It is possible to understand the situation of children affected by AIDS through literature review, situation analysis and discussions. The problem can be generalized, solutions can be mooted and programs devised. But without attention to context, these “solutions” may be inappropriate; and, in consequence, they may actually worsen the problem.

Contextual analysis precludes dealing with a perceived problem in a piecemeal way. It necessitates understanding the environment in which that problem or crisis unfolds. Pantin has graphically described the demands of this approach:

“First, you get in there and listen to the people. You listen to them for periods varying from a year to three years before attempting any organized project. In fact, even when you start doing something with them, you never stop listening. You listen until you are tired of listening and then you listen some more. You listen until all the cultural arrogance has been drained from your mind and you really begin to hear the voice of the people as the important element in their own development and as far more important than the wonderful schemes and ideas that are turning around in your busy little brain” (Pantin, 1989).

In other words, only through open-minded observance of daily life, and a considerable investment of time, does it become possible to understand the enormous depth and resilience of local cultures. This is in many ways the antithesis of problem-oriented approach, in which programs are designed to “respond” to perceived “situations,” to “fix” things that are thought to be dysfunctional. Development workers who proceed along the latter path overlook the fact that ordinary people have considerably more skill and a much greater vested interest than outsiders in overcoming their own problems. In consequence, while lip service is paid to the strength of local cultures, existing practices may be disregarded for the sake of project design.

Development experience is rich in examples of programs that originate in situational analysis but undermine community coping, disempower beneficiaries and thus work against the development of sustainable, locally owned initiatives. Salole puts it this way.

“A knee jerk response to a specific stimulus may well address that problem adequately, but it is also likely to affect other aspects of the finely balanced intricate membrane that constitutes the social environment and coping mechanisms. The evolution of resilient coping mechanisms has resulted in a myriad of interconnected and exquisitely interdependent responses; and it should be obvious that we should, at the very least, have an inkling about what is already going on before we invent bad copies of coping mechanisms that people have evolved for themselves. It is ironic that, despite the abundance and vitality of voluntary associations, [so many of them] have been completely overlooked as partners or agents in development work.”

In part, this is because voluntary efforts at the community level do not fit easily into standard programming molds. Baseline surveys, strategic plans, detailed monitoring systems and evaluations are standard practice on the part of international agencies. These are more easily conducted without

⁸ This and the next section draw extensively on Salole (1991).

directly involving community groups, which may not adhere to externally-established norms. The importance attached to such techniques speaks volumes about the donor orientation of external agencies and the corresponding lack of community perspective. The real accountability of such projects may often be to funding agencies and external organizations rather than to the communities themselves.

Box 1: Do we listen to what children have to say?

Children's voices are particularly difficult to hear in our busy schedules. But the perspective of children may provide us with missing pieces to the jigsaw of development. During an internal evaluation of FACT's orphan visiting program, children were asked to act out role plays of what they considered to be "good" as opposed to "bad" visits by volunteers. In the ensuing discussion, it emerged that, in the opinion of some children, volunteer visits were for the benefit of guardians rather than orphans. Sometimes, children were not even greeted or spoken to during visits. To call the initiative an orphan visiting program was a misnomer—it was really a guardian visiting program (Lee, 1999; Foster et al, 1997).

Community responses

Throughout Africa, the resilience of people is reflected in an extraordinary proliferation of community initiatives to deal with the impact of AIDS on children. Over the past decade, thousands of groups have recognized the increasing vulnerability of children and are responding with ingenuity. Such attempts to provide support for orphans and vulnerable children are hardly known outside their immediate locale. They have been little studied or documented. Few external organizations have sought to partner grassroots associations or provide them with additional resources, and few networks exist to support their development.⁹

Most community initiatives grow out of the concern of a few motivated individuals who work together to support vulnerable children. They spring from a sense of obligation to care for those in need, in a context characterized by inadequate or non-existent public services. Associations are started informally, by families, neighbors and church groups. Actions are spontaneous, informal responses driven by seeing or knowing about a situation requiring attention. In fact, most activities are carried out by concerned charitable women, widows and mothers, who see their involvement as "ministry."

For those interested in grassroots development, this proliferation of community-led activities to support vulnerable children is not surprising. On other concerns, and in many places, communities have developed processes to cope with similarly difficult situations.¹⁰ Even the poorest and most vulnerable people have set up resilient and ingenious coping mechanisms such as self-help groups, burial associations, grain loan schemes and rotating credit and loan clubs (Lwihula & Over, 1995;

⁹ As far as I know, no formal study of community initiatives has been conducted and published. Information presented here is based on a study of community responses from Zambia (USAID / UNICEF / SIDA / Study Fund Project. 1999c). It is also based on the author's research on community coping mechanisms: assessments of orphan support programs in Zimbabwe and Malawi in 1999/2000; focus group discussions with delegates from African countries at conferences on orphans and vulnerable children in Lusaka (2000) and Harare (2001); and insights gained from supervision and evaluations of seven community-based orphan support ("FOCUS") programs supported by FACT during 1993-2000 (Lee, 1999, USAID, 2000; Phiri et al, 2001; UNAIDS 2001).

¹⁰ For a detailed review of these informal social support coping mechanisms refer to UNAIDS, 1999

Mutangadura, 2000). These methods of coping are positive, successful aspects of everyday life that are non-sensational and almost invisible to outsider and insider alike. It is therefore not surprising to find that community orphan-caring initiatives are overlooked. As Salole points out, writing about community coping mechanisms:

“Indeed the very intimacy and familiarity that the ordinary person has with these institutions are so much a part of the social fabric that they are often not recognized or identified *even by their own members* as an integral part of the development process. In some cases these institutions are regarded as archaic and redundant even by individuals who take part in their activities. Perhaps it is a case of being so close to the phenomenon that one cannot see its value or focus on its potential. To some extent one also must allow for the insidious way in which people who are ‘educated’ are somehow made to feel that they must eschew or repudiate what is regarded as ‘traditional.’ This results in the curious phenomenon whereby people who should know better, who have personal experience of functional traditional coping mechanisms, are the first to deny their role in ordinary life.”

Misconceptions abound concerning the existence and effectiveness of community coping mechanisms. External organizations, and especially those lacking local knowledge of communities, have a tendency to view these efforts as weak and failing. Such a pessimistic line of thinking is pervasive, even in progressive development-oriented organizations.¹¹ The answer is then to step in with prescribed external remedies, in order to rescue the population from misery and desperation. Viewing the poor or disadvantaged as victims in need of rescue is especially congruent with the interventionist approaches of organizations with a service delivery orientation. And the provision of grants to establish programs that attempt to mitigate the impending orphan crisis has the potential to exaggerate this tendency. As agencies begin to appreciate the nature and scale of the disaster, there is a tendency to imagine doomsday scenarios that have little to do with reality.¹²

Yet in many places communities are not disintegrating and support systems are not faltering. In fact, just the opposite is happening. Communities are responding to the impact of AIDS with innovative support systems. And they are doing this largely in the absence of any external assistance, relying on their own resourcefulness and resources. Just as in the past, they are coping by adapting – not simply relying on existing, customary systems; but responding to changing situations by developing new institutions, such as the recently established associations of people coming together to support vulnerable children. Maxine Ankrah’s prediction a decade ago that African communities and clans would respond by creating wholly new structures among populations devastated by AIDS, is being confirmed with each passing year:

“New associations based on common emotional bonds of caring beyond kinship ties will be necessary to support some vulnerable members. However, for such to prove

¹¹ As in this quote from the UNDP (1993): “Because of the way that infection is clustered in families, occupations and geographical areas, the impact of multiple illness and death is much greater than the accumulated individual losses. Households and communities can quickly cease to be viable social or economic units. The trauma of grieving death after death can induce a feeling of powerlessness and an inability to act. Support systems falter with the seemingly endless demands made upon them.”

¹² Paradoxically, the welcome expansion of international support for orphans and vulnerable children may have resulted from exaggeration of the impact of AIDS. Shortly after President Clinton’s announcement that additional funds would be designated for family and community care programs as part of the Life Initiative, the author was in Washington. One NGO officer informed him that the Initiative was born after active lobbying by his agency to persuade the US government of the destabilizing effect of hordes of poorly socialized orphans and street children in AIDS-affected countries in Africa. There is no empirical evidence to support such a scenario.

lasting in the troubled socio-economic context of sub-Saharan Africa, these will need strong links to or derive their legitimacy from the resilient, traditional social network, the African kinship system... AIDS portends more, rather than a less central role for the family and clan" (Ankrah, 1993).

Principles of community initiatives¹³

Community initiatives for vulnerable children are characterized by features typical of other community coping activities. The principle of *reciprocity* is a prominent characteristic of people living together in traditional societies. In many AIDS-affected communities, the mechanism that keeps households from destitution consists of material relief, labor and emotional support provided by community members. In Tanzania, for example, there is a long tradition of social support groups; members assist one another in routine ways by helping to cultivate one another's fields and by contributing labor, money or food to one another at times of special need such as sickness and funerals, or on special occasions such as marriage ceremonies (Mukoyogo & Williams, 1991).

Seeking relief from family, friends and neighbors is a coping strategy for households affected by AIDS that is not unique to the epidemic. This type of community "safety net"—the provision of short term relief and assistance by individuals and organizations within the community—is a common response to an array of disasters, both natural and man-made (Donahue, 1998). At times of distress such as bereavement, all community members are obliged to participate and contribute towards funeral costs. For those who participate, the safety net is the poor person's life insurance. These supportive actions are part of a clearly understood system of solidarity that ensures that individuals will receive the same assistance to that they provide if affected by similar adversity. Culture reinforces such arrangements through oral tradition: "*What has befallen me today will befall you tomorrow*" is one such example from African proverbial lore (Hamutylenei & Plangger, 1987).

Consensus-based decision-making is a feature of community initiatives. In contrast to many externally initiated projects, community initiatives may take months or years to become established as community members take time to assess and discuss matters and arrive at consensus. Each community considers the factors that contribute to vulnerability in their area and establish criteria to identify the most vulnerable members. Prioritization of which vulnerable children should receive assistance involves consensus-based decision-making. Typically priority is given to children who are living on their own or those who have lost both parents to AIDS. Others include children who have lost one parent and have no assistance from the extended family, and children living in grandparent-headed households. Some of the children deemed to be the most vulnerable are not orphans but, for example, children with a parent who is terminally ill. Sometimes, children whose parents are alive are referred to as orphans in the local language because of their dire situation. These children may be termed "social orphans" as opposed to "biological orphans"; community-owned programs do not allow such children to fall through the cracks because of rigid adherence to pre-defined, externally imposed categories of vulnerability.

As activities expand, groups establish committees to enable more effective functioning. Members make contributions in cash or in kind to the association. They record details of money raised through donations and income generating projects and monitor accounts. They make decisions about which households should receive money to pay fees enabling children to return to school. They produce reports are given concerning the functioning of the organization. And they allocate tasks such as

¹³Much of this and subsequent sections draws on a survey, conducted in Malawi and Zimbabwe, which was commissioned by the Displaced Children and Orphans Fund and considers how effective orphan support programs can be taken to scale (Phiri et al, 2001).

visiting, raising funds or liaison with community leaders. Committees develop plans concerning the development of the initiative and make important decisions through discussion and consensus.

Self-reliance is another prominent feature of community initiatives. Resources are mobilized from within the community. Individuals donate their labor, materials and time to visit orphan households, take young or sick children into their homes, and carry out repairs to dwellings or assist in ploughing orphans' fields. Volunteers donate food, agricultural inputs and clothing to destitute households and arrange for adolescent orphans to earn money by working in others' fields. Donations are obtained from local businesses, religious organizations, traditional leaders and individual benefactors. Income is raised through projects such as sewing and knitting, vegetable gardens and animal husbandry.

Community members in Zimbabwe were asked about the problem of orphans in their community. Few responded with fatalism and acquiescence. Some responded that in view of poverty, there was little they could do: "We cannot help, although we have love, because life is difficult." But many more stated that although they were poor and could not give much material help, they were attempting to alleviate the desperate situation faced by orphans in other ways. Respondents wanted to recruit others to help in orphan support and felt there was need for each member in the community to share the burden of care and support (Foster et al, 1997b).

Local leadership is another critical principle underlying community mobilization and is critical in all areas of response. The vision of the leadership ultimately determines the quality and magnitude of response, as well as possibilities for broad participation. A good example of this can be given from Malawi, where the chief of one village was a woman who was also the chairperson of the Village AIDS Committee. She offered her land to the committee to grow crops to support orphans. The chief and her sons were the first to start cultivating the land, often waking up at the crack of dawn. She was asked what made people in her village willing to volunteer to help vulnerable children. She replied that rather than simply ordering her village to contribute resources to help orphans, she demonstrated commitment and set an example. When she addressed the village and requested help, people were willing to participate because they had come to share the vision of the leader.

Voluntarism is the cornerstone for community support initiatives. The altruism and expressed commitment of volunteers emanate from a sense of community ownership and cohesion, reinforced by religious affiliations and orientations. Responses are volunteer driven and involve motivated individuals who give love and care for children "from their hearts." An indication of their level of commitment is that, within 25 community-based orphan support programs associated with two NGOs in Zimbabwe, only one volunteer out of 800 dropped out over several years of program history (Phiri et al., 2001).

Innovation is another feature of community initiatives. As volunteers become aware of problems they develop strategies to bypass or overcome constraints. Child headed households are a case in point. Such households are a manifestation of the weakened extended family safety net. While some become established because there are no known relatives, in a majority of cases there are known relatives, sometimes living nearby, but these family members are unwilling or unable to bring orphans into their own families. Thus child-headed households may be viewed at the same time as resulting from the failure of the extended family safety net and as being a new form of coping. Some community initiatives respond to the desperate plight of children living alone in these households. In extreme cases, volunteers visit these children every day, in some cases taking children into their own homes for short periods – for care during illness, for example, or as part of a regular arrangement that allows young household heads to attend school while neighbors mind the pre-school children. There are many other examples of innovation of community initiatives that enable people to develop culturally appropriate responses to difficult situations.

Association with or reliance upon *faith-based organizations* is a prominent feature of most community initiatives. In all societies religious organizations and movements are a feature of the landscape not just in religious and spiritual terms but also in relation to other development endeavors including education, health, other social development activities, and even in politics. In fact, religion is an integral, if not--in many cases--the most important part of a community's life. It is central to all the critical milestones of a large majority of the members of the communities, including birth, marriage and death. The grouping of adherents to faith-based organizations represents a community within a community. Faith-based organizations have credible leadership, existing structures and effective channels of communication that are present at all levels of society. Faith-based institutions convene people on a weekly basis and can speak to them with great credibility and authority. They also have experience in creating interactive information sharing among peer groups—such as different age groups, youth and women.

It is not just the scale of the AIDS pandemic that presents a fundamental challenge to the world, but also its duration. Long-term commitments are necessary to control this disease. Faith-based organizations have proven their sustainability through continuous presence in human communities for centuries. They have withstood conflict, natural disaster, political oppression and plagues. Members of religious organizations have demonstrated commitment to respond to human need based on the moral teachings of their faith, and they do this voluntarily and over long periods of time. As HIV/AIDS continues to create a “caring deficit”—eroding the capacity of communities to care for those affected—faith-based organizations will be critical to sustaining the ability to address the impact of the disease.

Do community initiatives meet the needs of vulnerable children?

Despite the creativity and commitment displayed by local communities, it is possible to question whether most initiatives are effective in meeting the needs of vulnerable children and their families. It is conceivable that the efforts of communities are unproductive and their activities ineffective in mitigating the impact of the epidemic upon children. Dealing with this question is not easy. In fact, few studies have been conducted on grassroots community initiatives or even on programs for vulnerable children implemented by community partners of NGOs.¹⁴ There are evaluations of some donor-driven programs, including some that have taken on community-based organizations as partners; but these are unlikely to be of much help in coming to valid conclusions. They are not typical efforts and they cannot tell us much about the nature and effectiveness of community initiatives. Furthermore, it is a mistake to think that the same techniques of appraisal used to assess projects of development agencies should be applied to community initiatives.

Community initiatives address the different impacts of AIDS on children in many different ways.¹⁵ Some of these are summarized in Box 2 below. Although it is not possible to

Box 2: Some components of community initiatives

Home visits
Love and care for children
Surrogate parenting
Promotion of child fostering
Day care for young children

¹⁴ Some of the more detailed descriptions and assessments of OVC programs that have helped in understanding community responses include: WAMATA, Tanzania (Mukuyogo & Williams, 1991); FACT/FOCUS, Zimbabwe (Foster et al, 1996; Lee, 1999; UNAIDS, 2001); COPE, Malawi, (DCOF, 1996; Donahue & Williamson, 1998; Hunter & Williamson, 1999); Caritas/Orphanaid, Swaziland (Makufa & Xaba, 2001).

¹⁵ Activities conducted by community based organizations and NGOs to support children affected by AIDS are reviewed in Foster (2000b)

<ul style="list-style-type: none"> Getting children back to school Raising money for school fees Income-generating projects Material support provided by neighbors Nutrition gardens Agricultural labor and household repair Accompanying sick children to hospital Referral to other agencies (e.g. social welfare, health) Advocating for children (e.g. school fees, rent, legal issues) Community schools and appropriate education and training Raising concerns with community leaders about sexual abuse, exploitation Organizing cultural, sporting and leisure activities Spiritual support and counseling
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analyze them all, it is perhaps important to draw attention to two of the main components of community initiatives whose effects are not sufficiently valued: visiting vulnerable people and attempting to supplement their income.

Visiting AIDS-affected households is a major element in community solidarity. Most visits are conducted by village women and consist of brief social calls to ensure the well-being of their neighbors. Sometimes these visits are incorporated into community programs. For example, in the FOCUS program of Family AIDS Caring Trust, in Zimbabwe – which has been replicated widely – volunteers identify all orphan households in their village and visit prioritized households at least twice a month (FACT, 1998; Foster et al. 1996). Households such as those headed by children and those with sick members may be visited daily for prolonged periods. Visits enable relationships to be established with needy families so that, when crises occur, household members may turn to visitors for support and advice. They also allow attention to the families' material needs. The absence of food, seed or blankets is noted and remedied. Practical chores such as cooking, washing, bathing children or collecting wood may be carried out. Training and counseling are provided. Visits enable the children's situation to be observed as well. Children who are out of school, in emotional distress or being abused are identified; and appropriate action can then be taken. The likelihood of abuse, exploitation and maltreatment of orphans lessens in communities where frequent visiting is occurring. Visits also enable spiritual activities such as prayer and the sharing of scripture reading and praise songs.

Despite the importance of volunteer visiting to needy households, surprisingly little attention has been given to this activity in agency reports on community initiatives. The very ordinariness of visiting carried out by groups of poorly-educated, untrained volunteers has prompted disregard for the value of this foundational orphan support activity. Sometimes, the most important aspects of community coping are so unremarkable they remain unnoticed by outsiders. Furthermore, the lack of attention to visiting, lack of recognition of community initiatives and lack of understanding of the resilience of community coping may be a reflection of the general lack of female perspective and world view in many situation analyses, policy documents, research studies and monographs on HIV/AIDS and development (Rosaldo & Lamphere, 1974).

Most community attempts to improve the lot of vulnerable children and households also make some effort to increase the income of beneficiaries. In Zimbabwe and Malawi, community gardens are often used for this purpose. The chief or another well-to-do leader donates a field; and members of the community, usually women, organize to tend it. The produce is used to support the needy in the community. Initiatives established by traditional leaders have become focal points for supporting orphans and have encouraged community members to establish other income generating activities to support vulnerable children as well.

In fact, the range of income supplementation activities is protean. Their purpose is often to pay school fees and to enable children to return to school. Assessments of the actual amount of income raised through such activities are discouraging. A review of income generating projects in an orphan support program in Zimbabwe found that 84 percent had monthly revenues of \$5 or less, and 14 percent generated between \$5 and \$12. This level of income, which is probably typical of initiatives elsewhere in Africa, has led government agricultural extension workers to conclude that

“These are get-together projects that keep women busy but out of business. They tend to be highly seasonal, die during the busy agricultural season, and in most cases have done little to improve the standard of living of rural folk” (Matshalaga, 1997).

Should one conclude that it would be better for volunteers to abandon such projects in view of the low income they generate in relation to the amount of work expended? Such a conclusion would be erroneous without consideration of a host of other important factors. The value of income generating projects goes much beyond the amount of money generated. The fact that people work together contributes to community solidarity, self-reliance and awareness of needs within different sectors of the population. In addition, income-generating projects, often carried out on a trial-and-error basis, may have the potential to produce higher returns if they receive the right kind of outside support.

In fact, community initiatives have improved the situation of thousands of vulnerable children, their families and communities. The positive changes that have been brought about as a result of these activities are easily observable to community members. They include

- an increase in material support for vulnerable groups;
- the establishment of income-generating projects;
- a strengthened community social safety net, brought about through increased support to vulnerable families (employment provision, assistance with agricultural and domestic tasks or house construction, and in-kind or cash contributions);
- reduced stigma as a result of regular visiting to households affected by HIV/AIDS;
- better adjusted children, who are drawn into social, cultural, sporting or educational activities;
- reduction in cases of sexual abuse and physical exploitation as a result of increased child protection;
- a noticeable increase in the number of children who have returned to school.

Understanding how communities assess the impact of their activities should be an important area of operational research by external organizations. The latter will likely show that, for local people, programs to support orphans and vulnerable children represent an extension of existing activities rather than the conception of new projects. Grassroots organizations do not conduct situation analyses before establishing activities—their organic linkage to the surrounding community ensures knowledge of stakeholders and available resources, as well as prior understanding of the problem's context. Similarly, local monitoring is different from that required by donors. It is an ongoing, informal process that allows frequent program adjustments to be made, based on trial and error assessment of impact; and it is far more flexible than the mid-project evaluations that often lead donors to make major program corrections. Moreover, community activities do not come to an end or wind down at the end of a specified period. The time scale and perspective of community coping is long term and altogether different from three- or five-year project and funding cycles of donors and their implementing partners. At stake is the very survival and well-being of the community itself.

Development of community initiatives

As they build on initial successes and gain the endorsement of community leaders (business people, respected figures in the church, chiefs and political leaders, health workers and agricultural development staff), community initiatives can grow into community-based organizations (CBOs) that carry out coordinated child support programs. Milestones in organizational development include the

appearance of regularly convened committees with defined responsibilities, approval of formal statutes, opening a bank account, setting up training activities, and creating monitoring and reporting systems. This progress is the result of decisions taken within communities themselves, albeit with advice and support from outsiders. It can greatly facilitate an expanded response to the situation of children affected by AIDS.

As they evolve, community initiatives can expand the *scope*, *scale* and/or *capacity* of existing activities. In broadening the *scope* of their programmes, local groups have begun to give increasing attention to subjects like child nutrition and growth, psycho-social support for vulnerable children, and HIV prevention. A growing concern among volunteers involved in community initiatives, in fact, is the increasing vulnerability of orphaned girls to sexual abuse and HIV infection. Yet the emphasis of community initiatives on vulnerable children has implied very limited attention to HIV/AIDS issues *per se*, despite the fact that the epidemic is tacitly acknowledged to be responsible for many parental deaths. This lack of emphasis on HIV/AIDS has positive effects: it reduces the potential for stigmatization. But, conversely, it may also limit the development of activities associated with HIV prevention.

It is imperative to link programmes that provide care and support for children affected by AIDS to programmes that work to prevent the spread of the disease (Schietinger, 1998). And in order effectively to address this issue, African communities must overcome a reluctance to discuss sexuality with young people. Fortunately, there is evidence that community initiatives are becoming more willing to face the difficult issues surrounding youth, sexuality and HIV prevention, even when their members are strongly religious. The involvement of young people in the provision of psycho-social support to orphaned children is an example of how vulnerable children's programming can enable such linkages to be made (UNAIDS, 2001b).

Even without expanding their scope, some initiatives have increased the *scale* of their activities through expansion, increasing coverage within a program area or incorporating volunteers and households beyond its existing borders. This increases the number of households, communities and organizations reached by effective services. Scaling-out has also occurred through replication, when people from other communities observe and copy community initiatives, or when external organizations facilitate such a process. Community programs become established and spread from one community group to another with surprising speed and effectiveness. For example, an itinerant Christian missionary, working with the home care programme of FACT in 1993, built on this experience to promote child visiting programmes among congregations associated with the Evangelical Fellowship of Zimbabwe. As a result, 22 separate programmes now involve some 720 volunteers from 99 churches. They provide regular visits to approximately 12,000 vulnerable children (see Phiri et al., 2001).. Box 3 provides an example of how another faith-based initiative has expanded.

Box 3: The Bethany Project

The Bethany Project is a Christian-based program to assist children affected by AIDS in Zvishavane, Zimbabwe – a small mining town in a communal farming district with a population of some 150,000. In 1995, following visits to various NGOs, a British volunteer established the Project in two wards, with the participation of 35 volunteers who were responsible for identifying orphans and vulnerable children, making regular visits and providing small amounts of material support. Each ward has 6 to 8 villages; and each village has a subcommittee, which meets once a month.

The program involved community members from the outset. Church leaders, chiefs and ward committees provided home-based assistance to orphans through involvement in house repairs and the provision of school fees. Volunteers were recruited from local churches and provided regular visits to vulnerable children living nearby. Volunteers received a token gift each year.

In 1997-99, the Project expanded to the remaining 16 rural wards, so that it covered the majority of the district. It involves 656 volunteers; and, to date, no volunteer has dropped out of the program. Children are placed in three categories: the neediest orphans (4,952); other children in difficult circumstances (3,052); and others who have lost one or both parents, but are not among the neediest (4,046). Only those in the first two categories (8,004 children) receive regular visits and material support. School fees, mostly for primary schooling, are provided for some 900 children. Five HIV prevention groups and seven income-generating projects have been established.

The Bethany project works well with other partners in the district including government structures, local NGOs and other members of the Child Welfare Forum. Relationships with the Department of Social Welfare have been particularly strong, and this has been beneficial to the Project. Since transport constraints make it difficult for Social Welfare Department staff to reach rural areas, they frequently accompany Project staff during site visits. The Project employs three staff, and the organization's budget for 2000 was around \$20,000.

The development of community initiatives should not lead one to conclude that it is necessarily desirable for them to become mini-NGOs, employing staff to carry out their work and growing increasingly dependent upon the financial assistance of outside organizations. Some community initiatives have indeed grown into successful employee-based organizations, but most should and will remain largely anchored in the hard work and commitment of volunteers.

Why are responses occurring in some places but not in others?

The fact that community-based programs spread so easily, and that so few volunteers drop out, has less to do with the skilled facilitation of outsiders than with the degree to which community members are committed to vulnerable children and the extent to which local cultures are capable of developing new coping strategies. The proliferation of community initiatives thus raises a number of questions. Why should individuals and communities choose to invest their effort in this particular issue? And are there factors that inhibit the evolution of community-based responses in certain places?

Community solidarity is obviously one factor underpinning community initiatives. The supportive actions of people who volunteer their time and skills to care for orphans, and provide food or clothing to the destitute, spring from a humanitarian concern that is combined with reciprocity. Through caring for others, community members endorse mechanisms that ensure assistance for their own children should they be affected by similar adversity. A chief in Masvingo Province, Zimbabwe, explained:

“When the Department of Social Welfare talked about the need to do something about the growing number of orphans, we initially said, ‘Why should the whole community look after orphans who have their own relatives?’ But after discussing the issue, we realized that the orphan problem was not just the responsibility of individual

households or relatives but of the whole community. At the rate people are dying, we realized that tomorrow any one of us could die leaving orphans who would have to be looked after by the community" (Matshalaga, 1997).

But reciprocity is not the only or even the most important motivation underlying this coping mechanism. Community initiatives are widespread, occurring even in situations such as urban settings where reciprocal economic and social relations are weak. *Compassion* is the chief factor underlying innumerable individual acts of kindness and care. Before they became part of community initiatives, volunteers were already involved in acts of caring for others, often simply because they witnessed a desperate situation and felt they had something to offer. There was little expectation of any tangible benefit in return for such benevolence, apart from perhaps an expression of gratitude by the recipient and an inner knowledge that a particular act had helped in some small way to alleviate distress. Day to day acts of care giving go on with little fanfare and there are no awards for those who have excelled in human kindness. Those in greatest distress—child-headed households for instance—are the families most likely to impose upon the resources and time of the community; but these very households are also least likely to ever be in a position to pay back anything to their benefactors.

What are the motivating factors for such acts of compassion? As already noted, one of the strongest is *religious belief*, which reinforces the practice of caring for those in need.¹⁶ Volunteers who visit and support orphans in Africa are usually strong members of the churches and mosques through which the programs are organized, and they are often also members of women's guilds. In Malawi, for example, the Muslim faithful work through *dawa* women's groups (similar in intent and mission to the Christian guilds) to support and visit orphans, widows and the terminally ill. Muslim Friday prayers are also used to raise money that goes into a community chest to assist orphans.

Religion aside, what might be termed "having a caring heart" is another factor motivating acts of compassion towards orphans and the needy. Although this attitude is not necessarily restricted to females, it is noteworthy that women are the driving force in the community care of orphans. Most of these women are mothers and many are widows who are themselves caring for orphans. Therefore, not surprisingly, many women believe they have particular gifts to care for vulnerable children. This stands in marked contrast to the tentativeness with which women approach the challenge of home health care for adults. Although these two activities do not differ substantially, orphan visiting programmes have grown much more quickly than community-based care for the terminally ill. Health workers sometimes make ordinary people feel that they have insufficient knowledge to do what is required to help those who are suffering from AIDS. But women volunteers are quite sure that they have expertise in child care.

In fact, women are exclusively in charge of children's preparation for adult life in much of sub-Saharan Africa. Their responsibilities are intimately bound up with survival strategies, coping mechanisms for the poor and safeguarding the continuation or viability of the domestic group. Moreover, while women are expected to offer their services freely, men often expect something in return for their contributions. The reasons for gender imbalance in orphan programs are thus not difficult to understand. Evaluations of orphan support programs repeatedly note the importance of taking steps to encourage greater male participation in child welfare activities.

¹⁶ Over forty verses in the Bible and many in the Koran refer to helping widows and orphans. The Bible teaches: "Religion that is pure is...to care for orphans and widows in their distress" (James 1:27). The Koran teaches: "it is righteousness to believe in God and...to spend of your substance, out of love for Him, for your kin, for orphans for the needy....and practice regular charity; to fulfill the contracts that you made; and to be firm and patient in suffering and adversity and throughout all periods of panic. Such are the people of truth, the God-conscious." (2:177). Other religious traditions incorporate similar philanthropic teachings.

A final reason why community members choose to become involved in local initiatives is *concern for societal well-being*. Traditional mechanisms that have evolved over years to maintain community cohesion are being threatened by the combined impact of a reduced number of prime-age adults, increased numbers of orphans and increasing numbers of destitute families. To make ends meet, survivors may engage in acts of theft and other anti-social behavior. The involvement of stressed community members in child welfare activities is not only a reflection of the importance they attach to protecting children, but also of their concern to maintain societal stability, structures and practices.

Nevertheless there are clearly a number of factors working against the evolution of strong community responses to the impact of HIV/AIDS on children in Africa. Most of the cases analysed in the preceding pages come from rural areas where traditional structures and customs are maintained. In environments like urban and peri-urban slums, resettlement areas and commercial estates, traditional leadership structures may be non-existent and coping mechanisms weak. And there, children may be expected to suffer the consequences: they are often more likely to drop out of school, suffer from hunger, fall prey to exploitation and be psychologically maladjusted. Without literacy and livelihood skills, they may become involved in crime, end up on the streets and eventually be vulnerable to HIV infection.

Migration plays a central role in the coping strategies of families affected by HIV/AIDS. With the onset of serious illness, some urban residents return to rural villages, fulfilling a wish to go home to die. On the other hand, strong rural to urban migration occurs when widows migrate to towns in search of work or partners. More than one half of young widows and one quarter of young widowers under 35 years in Uganda moved from the household of their late spouse to earn money or for remarriage (Ntozi, 1997b). Mobility is especially common in adolescents affected by HIV/AIDS (Foster et al, 1997). Children accompany a parent in many cases, or are relocated within the extended family before or following parental death (Foster et al, 1995). Selective migration of orphans from rural to urban areas can produce clustering of orphan households in poor slum areas (McKerrow, 1996), where community initiatives are unlikely to evolve easily. Yet these are precisely the places where orphans are in greatest need of help.

In situations where coping capacity is low, it may be necessary to provide substantial external support to encourage the emergence of community responses. Participatory assessments enable the strength of community coping mechanisms and potential for community mobilization to be assessed through discussion of the community's needs, resources, gaps, environment, economy. Even within some of the most dysfunctional environments, it is possible to find elements of potential or actual community—such as the community of people belonging to faith-based organizations—which enable local initiatives to be nurtured. In difficult areas, some NGOs carry out community building activities enabling people and organizations to come together to envision how their ideal community should look, and then to work out plans for mobilizing all of the community's resources in order to achieve their visions. Still, it may be necessary to help local residents meet their most pressing needs before they are in a position to respond to a facilitator's efforts to establish community initiatives. There is a limit to what people can do in very difficult circumstances.

Partnerships: the key to supporting community initiatives

Though most community initiatives have been established without external facilitation, they can be strengthened and helped to expand through the involvement of external allies. In this regard, partnerships between community groups and outside organizations, both national and international, are key to the development of sustainable and effective responses to the needs of children affected by HIV/AIDS. Community *initiatives* have the potential to become community *organizations* involved in comprehensive HIV/AIDS prevention and mitigation activities, and to extend their work into other areas of development.

A true partnership depends upon mutual understanding and respect. Unfortunately, however, most external actors have a great deal to learn about the nature and diversity of community initiatives, including their organization, evolution, needs, capacities and limitations. Impelled by the need to produce quick and measurable results, and to limit risks, both NGOs and international agencies tend to retain firm control of any local programmes they support. Although external organizations frequently recruit volunteers from within the communities where their programmes operate, ownership of service delivery programs resides with NGOs, government departments or the private sector. This may increase the likelihood of short-term achievement of project goals and objectives, but it frequently fails to ensure long-term impact and sustainable development.

Outsiders not only tend to discount the organizational ability and technical competence of local people. They also often fail to understand the significance of kinship ties in building a successful response to the ravages of AIDS. In fact, there is mounting evidence that the ineffectiveness of many efforts to contain the epidemic may in part be the result of agency-initiated, program-oriented approaches that focus on individual behaviors and fail to involve clans and extended families, acting in the name of their members, in the development and ownership of effective HIV prevention activities.¹⁷

“One reason for neglect of the clan may lie in the conceptualization of problems such as the ‘AIDS orphan’ or the ‘person with AIDS’ largely from [a perspective that originates] outside Africa. These concepts tend to focus attention on the individual rather than on the African family and community, which are at the center of much of African social life. The fact that the African clanship system has not noticeably responded to AIDS, therefore, may be more because of its neglect with respect to the newly created NGOs than because of the system’s inability to respond. As AIDS increasingly affects women and children through this century, methods of protecting them must emanate from within acceptable structures with the capacity to sustain as well as to generate effective actions. Fundamentally, the clan must protect itself. This it can do when it is recognized, encouraged, and supported to serve the interests of women and children” (Ankrah et al, 1994).

Building functioning partnerships implies tackling these failings. Both local and international organizations must recognize that families and communities are the first line of response to children affected by AIDS; they are carrying and will continue to carry the primary burden of protecting and caring for orphans and vulnerable children. Their cultures and proficiencies must be understood and their ability to serve those in need must be strengthened.

To accomplish this requires, in most cases, a willingness on the part of external organizations to resist the temptation to engage in the direct implementation of externally designed programmes – channelling available resources instead toward promoting the kind of intermediary organizations that can strengthen existing community efforts and help local people to be more effective in their assistance to vulnerable groups. Certainly, NGOs have a vital role to play as intermediary organizations, building local capacity and facilitating the development of local initiatives. Training, information and the provision of support visits by those with facilitation skills can improve the capacity of fledgling community initiatives, transforming them into sustainable community-based organizations. The provision of small grants can enable the latter to increase their scope and coverage, freeing

¹⁷ Many effective peer education programs involve strong ownership by sub-communities such as the community of sex workers, single women or youth. Similarly, failure to address community perceptions of HIV/AIDS prevention may account for inability to generate effective community-led responses. These perceptions may not center around individual behavioral change. For example, traditional leaders in a rural community in Zimbabwe located the source of the AIDS problem within the context of the breakdown of social norms observed by past generations and proposed solutions involving community-based responses working with youth and employing traditional methods of sex education. This contrasted with the approach of political leaders, who wanted to prevent high-risk behavior among individuals (Laver, 1999).

volunteers from the need to raise money, enabling them instead to provide direct support to vulnerable children.

External organizations that are now dedicated primarily to service delivery can be encouraged to become facilitating organizations. And existing intermediary organizations can be helped to expand their role, so that they can more actively support other CBO and NGO responses. Measures that can facilitate the expansion of the role of intermediary organizations include

- building the organizational capacity of local initiatives;
- helping organizations develop a vision for scaling-out;
- providing additional financial resources linked to scaling-out;
- increasing the ability of governments to monitor initiatives that assist AIDS-affected children; and
- strengthening national coordinating mechanisms in this field.

Scaling-up and the diversity of community initiatives

Scaling-out is not the same thing as scaling-up. The first term refers to the horizontal expansion of existing programmes, through replication and the growth of capacity to serve greater numbers of people, already discussed above. The second, however, has to do with discovering successful models and proposing them for implementation in many other parts of a country or region. One of the fundamental questions in the area of support to vulnerable children is whether, and when, the latter approach is appropriate. The recent *Situation Analysis of Orphans and Vulnerable Children in Zambia* presents the dilemma well. In a section entitled *The absence of solutions that can be brought to scale*, the authors write:

“[There is an] absence of any concrete solution, or approach to a solution, that would provide for more systematic and comprehensive family/community support and that could be brought to scale. Projects and activities are myriad.... Yet all are essentially small-scale, local, idiosyncratic to the circumstances for which they were created, not necessarily replicable on a large-scale or in a different environment. What is at issue is the need for courageous thinking that can go beyond existing ways of providing support and encouragement to families and communities.... The challenge is to use all the existing social and support structures...while at the same time endeavoring to devise new approaches that will enable families and communities to cope...” (Sampa et al, 1999).

This line of thinking is currently prevalent: community responses are diverse, so it is necessary to search for a new, systematic response to the situation of children affected by AIDS. If only governments and other agencies developed a sense of urgency, the argument goes, an ingenious strategy could be devised that would facilitate implementation of a scaling-up program.

The problem is viewed from the perspective of strategists looking for over-arching solutions and large-scale programs. But another perspective should be paramount. International and national agency strategists must realize that the problem is not primarily their own. The problem of orphans belongs to affected communities, and many are already in the process of constructing context-appropriate solutions. When viewed from this perspective, the primary responsibilities of outside agencies are to strengthen the programs, activities and endeavors already initiated by communities whose children are affected by AIDS.

Existing ways of providing support and encouragement to families and communities form the basis of the solution. Unlike the situation that exists within many institutions at national and international levels, a sense of urgency already prevails at the community level. Moreover, a number of community groups are already bringing their solutions to scale by expanding their initiatives, activities and programs both within and beyond their own communities. When viewed from this perspective, the main problem for

external agencies is not the absence of overarching solutions but rather the constraints imposed by bureaucratic rigidity and the organizational ethos that prevents them from responding appropriately. Institutional inflexibility limits agencies' abilities to adapt programming to support the myriad small-scale, idiosyncratic sustainable responses that communities have developed.

In practice, scaling-up and scaling-out can be seen as complementary activities; there is considerable overlap between them. Thus implementing organizations may request support from resource organizations in order to expand their activities and scale-out their existing programs. Or resource organizations may actively promote scaling up of programs by meeting with implementing partners and helping them to plan to expand their programs. In order to maximize expansion of effective programming, it is important that scaling-up initiatives support existing scaling-out activities of implementers – promoting and building upon community-owned initiatives.

For the specific purpose of achieving scale, external change agents could also engage in the systematic and strategic mobilization of communities to respond to the situation of affected children and families where there is a need to do so. But scaling-up should not be imposed on implementing or intermediary organizations. Unfortunately, the late entry of international organizations into the field of assistance for AIDS-vulnerable children creates pressure for them to expand their programs before they have consolidated their experience, and at a time when neither they nor their partners have adequate operational capacity. The problem is exacerbated by the fact that agencies are recruiting staff from implementing organizations, which has the potential to strengthen one while weakening the other.

In fact, serious concerns have recently been raised about the provision of external support in ways that undermine local efforts (UNICEF / USAID / UNAIDS, 2001). If channeled in an inappropriate manner, even relatively small amounts of material assistance, provided to the neediest households, can undermine community coping strategies. Wrongly targeted assistance can change the nature of the community solidarity and distort the motivations that usually drive local initiatives (Box 5). While there is frequently a need at the community level for some basic funding or for specific resources, this type of support must be paired with efforts (such as technical assistance in organizational development and resource mobilization) that will enable participants to continue to make a difference after shorter-term funding is no longer available.

Box 5: The danger that external initiatives will undermine community coping

One local organization in a remote rural area established and then expanded a program that successfully mobilized volunteers to support vulnerable children. Without contacting or acknowledging the local organization, an international agency based outside the area invited volunteers from the existing community-based program to attend its training workshops and provided them with substantial payments. This undermined the voluntarism developed by the local organization and risked compromising the sense of ownership for child support activities painstakingly established by community groups.

There is a proverb from the Congo that warns: "When you call for rain, remember to protect the banana trees." In other words, the provision of external resources, can, if we are not careful, actually make matters worse by flattening local responses. External agencies would do well to remember that community initiatives are the front line response to orphans and vulnerable children and build their responses accordingly.

Box 6: Can external agencies successfully scale up local initiatives to assist children affected by AIDS?: A summary of constraints

- lack of capacity on the part of implementing organizations to expand programs;
- lack of vision within implementing organizations, whose members are satisfied with delivering existing services to a defined community;
- concerns about the sustainability of an expanded program, if the promoting organization should discontinue its support;
- lack of skills to deliver expanded programs, especially if local organizations that have experience in implementation are asked to facilitate service delivery by other organizations;
- top down donor approaches to scaling up, which weaken ownership on the part of local people;
- short time frame with pressure for rapid results from external organizations;
- different agendas of foreign and local organizations.

References

- Ankrah, E.M. (1989). AIDS: A research problematic. *Social Science & Medicine*, 293, 265- 279.
- Ankrah, E.M. (1993). The impact of HIV/AIDS on the family and other significant relationships: the African clan revisited. *AIDS Care*, 5, 5-22.
- Ankrah, M, Mhloyi MM, Manguyu, F & Nduati, RW. (1994) Women and children and AIDS. *AIDS in Africa*, ch 25, 533-546, eds Max Essex, Souleymane Mboup, Phyllis J Kanki & Mbowa R Kalengayi, Raven Press,, NY, 1994
- Barnett T & Blaikie P. (1992) *AIDS in Africa: Its present and future impact*. London: Belhaven Press, 1992.
- Bos E (1991) *Projecting the number of AIDS orphans in one African country*. Population and Human Resources Department, World Bank
- Caldwell, J.C. (1997). The impact of the African AIDS epidemic. *Health Transitions Review*, 7 (suppl. 2), 169-188.
- Chin J (1990) *Current and future dimensions of the HIV/AIDS pandemic in women and children*; WHO/GPA, July 1990
- Costigan A & Waring B, (1996) *From margin to center: Towards an advocacy agenda for AIDS affected children and youth*, XIth International Conference on AIDS, Vancouver, 1996, Abstract TuD485
- DCOF (1999) *Community mobilization for orphans in Zambia: An assessment of the orphans and vulnerable children program of Project Concern International*. Displaced Children and Orphans Fund and War Victims Fund, Washington.
- DCOF/COPE, (1996). *Developing Interventions to Benefit Children and Families Affected by HIV/AIDS: A Review of the COPE Program in Malawi for the Displaced Children and Orphans Fund..* Displaced Children and Orphans Fund and War Victims Fund, Washington.
- Donahue, J. (1998). *Community-based economic support for households affected by HIV/AIDS*. Discussion papers on HIV/AIDS care and support No. 6. Arlington, VA: Health Technical Services (HTS) Project for USAID.
- Donahue J & Williamson J. (1998) *Community mobilization to address the impacts of AIDS: A review of the COPE II program in Malawi*. Displaced Children and Orphans Fund and War Victims Fund, Washington.
- Drew, R.S., Foster, G., & Chitima, J. (1996). *Poverty - A major constraint in the community care of orphans: A study from the North Nyanga District of Zimbabwe*. *SafAIDS News*, 4, 14- 16.
- Drew, R.S., Makufa, C., & Foster, G. (1998). *Strategies for providing care and support to children orphaned by AIDS*. *AIDS Care* 1998, 10 (Suppl), S9-S15.
- Foster, G. (1997). *Orphans*. *AIDS Care*, 9, 82-87.
- Foster, G. (1998a). *HIV and AIDS: Orphans and sexual vulnerability*. P. Kilbourn & M. McDermid (Eds), *Sexually Exploited Children: Working to Protect and Heal* (pp216-232). Monrovia: MARC.

Foster, G. (1998b). Today's children - Challenges to child health promotion in countries with severe AIDS epidemics. *AIDS Care*, 10 (Suppl. 1), S17-S23.

Foster, G. (2000a). The capacity of the extended family for orphans in Africa. *Psychology, Health & Medicine*, 5, 55-62.

Foster G. (2000b). Responses in Zimbabwe to children affected by AIDS. *SafAIDS News*, 8(1), 2-7.

Foster, G., & Williamson, J. (2000). Impact of HIV/AIDS on children in Africa: A review of current knowledge. *AIDS*, 14 (suppl 3), S275-S284.

Foster G & Germann S (2001) The orphan crisis. In *AIDS in Africa*, ed Max Essex et al. (in press) Foster, G., Shakespeare, R., Chinemana, F., Jackson, H., Gregson, S., Marange, C., & Mashumba, S. (1995). Orphan prevalence and extended family care in a peri-urban community in Zimbabwe, *AIDS Care* 7, 13-17.

Foster, G., Makufa, C., Drew, R., Kambeu, S., & Saurombe, K. (1996). Supporting children in need through a community-based orphan visiting programme. *AIDS Care* 8, 389-403.

Foster, G., Makufa, C., Drew, R., & Kralovec, E. (1997a). Factors leading to the establishment of child-headed households: The case of Zimbabwe. *Health Transition Review*, 7 (Suppl 2), 155-168.

Foster, G., Makufa, C., Drew, R., Mashumba, S., & Kambeu, S. (1997b). Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe. *AIDS Care*, 9, 391-406.

Foster, S. (1995). *ADZAM - a Study of Adult Diseases in Zambia - Final Report*. London: Overseas Development Agency.

Gates B & Gates M. (2000) Immunizing the world. *Newsweek*, December 2000-February 2001, 84-85. Washington, US.

Gavin L (2001) A household- and community-level investigation of children in Zimbabwe who are affected by the HIV/AIDS epidemic. PACT Zimbabwe, Harare.

Gilborn LZ, Nyonyintono R, Kabumbuli R & Jagwe-Wadda G. (2001). Making a difference for children affected by AIDS: Baseline findings from operations research in Uganda. Population Council, Washington DC.

Hamutyinei MA & Plangger AB (1987) *Tsumo-shumo: Shona proverbial lore and wisdom*. Mambo Press, Gweru, Zimbabwe

Hunter S (1989) Preliminary report on the project for the enumeration and needs assessment of orphaned children in Uganda. Poster presentation, IV International Conference on AIDS in Africa, Marseilles

Hunter S, (1990) Orphans as a window on the AIDS epidemic in sub-Saharan Africa: Initial results and implications of a study in Uganda. *Social Science and Medicine* 31:681-690, 1990

Hunter, S. (2000). *Reshaping societies: HIV/AIDS and social change*. New York Hudson Run Press.

Hunter, S., & Williamson, J. (1998). *Children on the brink: Strategies to support children isolated by HIV/AIDS*. Washington DC: USAID, 1998.

Hunter, S., & Williamson, J. (2001). Children on the brink: Executive summary: Updated estimates & recommendations for intervention. Washington: USAID.

Kaleeba N, Kadowe JN, Kalinaki D & Williams G. (?2000) Open secret: People facing up to HIV and AIDS in Uganda. Strategies for Hope, 15 Action Aid, London

Larson A, (1989), Social context of HIV transmission in Africa: Historical and cultural bases of East and Central Africa sex relations. Review of Infectious Diseases 11, pp. 716-731

Laver, SML (1999) Generating a response to HIV/AIDS prevention in M'hondoro and M'sengezi communal lands: Lessons learned and shared. In AIDS and African Smallholder Agriculture, eds G Mutungudura, H Jackson, D Mukurazita, Safaids, Harare

Lee, T. (1999). FOCUS Evaluation Report: Report of a participatory self-evaluation of the FACT Families, Orphans and Children Under Stress (FOCUS) programme. Mutare: FACT. Available at www.safaids.org.

Levine, C., & Foster, G. (2000). The White Oak Report: Building International Support for Children Affected by AIDS. New York: The Orphan Project.

Lwihula, GK (1999) Coping with the AIDS pandemic: The experience of peasant communities of Kagera region, Tanzania. In AIDS and African Smallholder Agriculture, eds G Mutungudura, H Jackson, D Mukurazita, Safaids, Harare

Lwihula, G & Over, M (1995) The role of indigenous savings and emergency assistance associations in coping with AIDS. Abstract TuD670, IX International Conference on AIDS and STDs in Africa, Kampala

Makame V, Ani C & Grantham-McGregor S (2001) Psychological well-being of AIDS orphans in Dar Es Salaam. (submitted for publication)

Makufa C & Xaba B (2001) Appraisal of CARITAS Orphanaid Programme. CARITAS, Mbababane, Swaziland

Matshalaga (1997). Sustainability of the community-based orphan/children in especially difficult circumstances care programme in Masvingo and Mwenezi through community income generating projects. UNICEF, Harare

McKerrow, N. (1996). Responses to orphaned children. Lusaka: UNICEF Lusaka.

Mukuyogo MC & Williams G (1991) AIDS orphans: A community perspective from Tanzania. Strategies for Hope, 5 (Action Aid / AMREF / World in Need).

Mutangadura, G.B. (2000). Household welfare impacts of mortality of adult females in Zimbabwe: Implications for policy and program development. Carolina Population Centre, University of North Carolina.

Nærland, V. (1993). AIDS: Learning to be more helpful. Kampala: Redd Barna.

Ntozi, J.P.M. (1997a). AIDS morbidity and the role of the family in patient care in Uganda. Health Transitions Review, 7 (Suppl), 1-22.

Ntozi, J.P.M. (1997b). Widowhood, remarriage and migration during the HIV/AIDS epidemic in Uganda. Health Transitions Review, 7 (Suppl), 125-144.

- Palloni, A., & Lee, Y.J. (1992). Some aspects of the social context of HIV and its effects on women, children and families. *Population Bulletin of the United Nations*, 33, 64-87.
- Pantin G (1989) Keynote address in *Children and Community: Progressing through partnership*. Summary report and conclusions: The Hague, The Netherlands: Bernard van Leer Foundation.
- Phiri, S.N., Foster, G. & Nzima, M. (2001). Expanding and strengthening community action: A study to explore ways to scale-up effective, sustainable community mobilization interventions to mitigate the impact of HIV/AIDS on children and families. Draft, Washington: Displaced Children and Orphans Fund of USAID.
- Preble E (1990) Impact of HIV/AIDS on African children. *Social Science and Medicine*, 31:671-680
- Robson, E. (2000) Invisible carers: Young people in Zimbabwe's home-based health care. *Area*, 32, 59-69.
- Rosaldo MZ & Lamphere L (eds) (1974) *Journal of Woman, Culture and Society*. Stanford, USA. Stanford University Press
- Rutayuga, J.B.K. (1992). Assistance to AIDS orphans within the family/kinship system and local institutions: A program for east Africa. *AIDS Education and Prevention*, 4 (Suppl), 57- 68.
- Salole, G (1991) Building on people's strengths: The case for contextual development. Seminar in Maseru, Lesotho, 25 - 30 November 1991, Bernard van Leer Foundation, November 1991.
- Sampa, S, Chitalu M & Kelly MJ. (1999) Volume 1; Bibliography: An annotated review of literature relevant to the situation of orphans and vulnerable children in Africa.. Situation analysis of orphans in Zambia, 1999 (draft); USAID/UNICEF/SIDA/Study Fund Project
- SAT (2001). Directory of support groups for people living with HIV/AIDS in Zimbabwe. Southern African AIDS Training Programme, Harare, Zimbabwe.
- Schietinger, H. (1998). Psychosocial Support for People Living with HIV/AIDS: Discussion Papers on HIV/AIDS Care and Support. No. 5. Arlington, VA: Health Technical Services (HTS) Project for USAID.
- Seeley JA, Kajura EB & Mulder DW (1995). Methods used to study household coping strategies in rural South West Uganda. *Health, Policy and Planning* 10(1): 79-88.
- Sengendo, J., & Nambi, J. (1997). The psychological effect of orphanhood: A study of orphans in Rakai district. *Health Transition Review*, 7 (Suppl), 105-124.
- SIAPAC (2001). A situation analysis of orphan children in Namibia: Overview of findings. Conference on Orphans and Vulnerable Children in Namibia, 8 May, 1998. Available from UNICEF, Namibia.
- UNAIDS, (1999), A review of household and community responses to the HIV/AIDS epidemic in the rural areas of sub-Saharan Africa, Geneva.
- UNAIDS (2001a). Caring for our children: Promoting community-based responses to children affected by AIDS . UNAIDS Best Practice Series (awaiting publication). Geneva: UNAIDS.
- UNAIDS (2001b) Investing in Our Future: Psychosocial Support for Children Affected by HIV/AIDS : A Case Study of Zimbabwe and Tanzania; UNAIDS Best Practice Collection. Available from www.unaids.org/publications/documents/children/children/JC606-InvFuture-E.pdf

UNDP (1993). The HIV epidemic as a development issue. United Nations Development Programme, quoted in Williamson (1995)

UNDP (undated) Building development projects in partnership with communities and NGOs: An action agenda for policy makers. United Nations Development Programme: The Regional Programme Division, Bureau for Asia and the Pacific, quoted in Williamson, 1995

UNICEF (1990) Children and AIDS: An Impending Calamity, New York, 1990

UNICEF (1991) AIDS and Orphans in Africa: Report of a meeting held in Florence, Italy, June 1991

USAID (2000) Background paper on children affected by AIDS in Zimbabwe, Harare, Zimbabwe.

USAID / UNICEF / SIDA / Study Fund Project. (1999a) Situation Analysis of Orphans in Zambia, Volume 1, Bibliography: An Annotated Review of Literature Relevant to the Situation of Orphans & Vulnerable Children in Zambia. Lusaka: Government of Zambia.

USAID / UNICEF / SIDA / Study Fund Project. (1999b): Situation Analysis of Orphans in Zambia, Volume 2, Data Review: Analysis and enumeration using existing data.. Lusaka: Government of Zambia.

USAID / UNICEF / SIDA / Study Fund Project. (1999c) Situation Analysis of Orphans in Zambia, Volume 3B: Community Response: A qualitative assessment of community response to high levels of orphanhood from 12 sites in Zambia.. Lusaka: Government of Zambia.

UNICEF/ USAID / UNAIDS (2001). Global framework for addressing the plight of children and adolescents affected by AIDS. USAID, Washington.

WHO (1990) A draft discussion paper on the care and support of children of HIV infected parents, Geneva, WHO, 14 September, 1990

WHO/UNICEF. (1994). Action for children affected by AIDS: Programme profiles and lessons learned. New York: World Health Organisation / United Nations Children Fund.

Williamson J (1995) Children and families affected by HIV/AIDS: Guidelines for action (Draft document produced for the Health Promotion Unit, UNICEF, 118pp)

Williamson, J and Donahue, J, (1998) Community Mobilization to Address the Impacts of AIDS: A review of the COPE II program in Malawi. Displaced Children and Orphans Fund, Washington

World Bank. (1997). Confronting AIDS: Public priorities in a global epidemic. Oxford University Press, New York

World Bank. (2001). Nongovernmental Organizations and Civil Society. : Key Documents/Working with NGOs. Introduction. Document at www.worldbank.org