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

Geoff Foster[1]

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[1]The author has been employed as pediatrician by the Government of Zimbabwe at Mutare Provincial Hospital from 1986 until the present. He was the founder and served as Director of Family AIDS Caring Trust (FACT) from 1987-2000; and he currently works as a consultant in research, evaluation and technical support of orphan and vulnerable children programs.

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UNRISD, Palais des Nations
1211 Geneva 10, Switzerland

Tel: +41 (0)22 9173020
Fax: +41 (0)22 9170650
E-mail: info@unrisd.org
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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 children[2]

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—

[2]This 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:

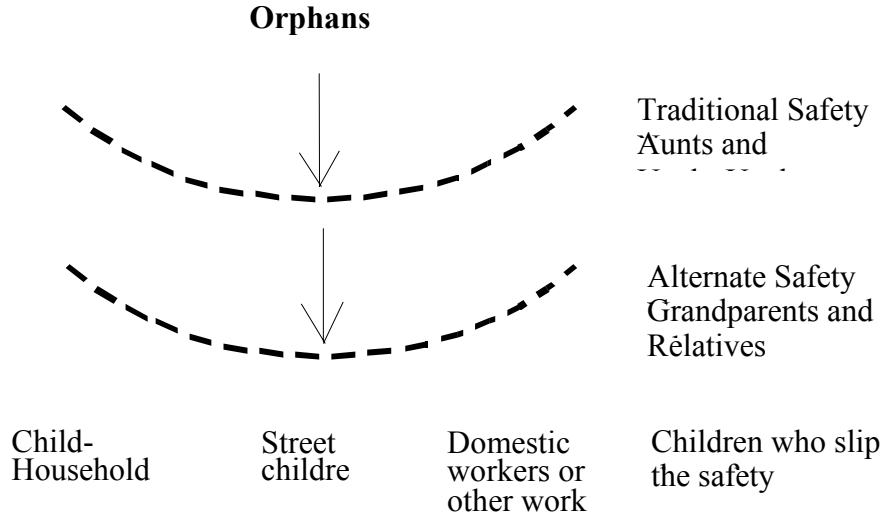

Figure: Model of the extended family safety net for orphans in Africa.

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 countries[3]. 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 AIDS[5]

[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 Ankrah, 1989; Barnett & Blaikie, 1990; [Conant, 1988]; Hunter, 1989

[5]For 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

[6]For 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.

[7]Some 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 c*ontextual 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