Child Vulnerability and HIV/AIDS in sub-Saharan Africa: What We Know and What Can Be Done

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INTRODUCTION

Among the many devastating consequences of the AIDS epidemic in sub-Saharan Africa, the rapidly growing orphan population demands particular attention. Today, over 12 million children in the region have been orphaned by AIDS, a population that is increasing by the minute as HIV-positive parents become ill and die from AIDS (UNAIDS/UNICEF/USAID 2004). Millions more children are living with chronically ill parents, and about three million are themselves infected with the virus. Estimates differ, but some organizations predict a tripling of orphan numbers in the next five years.

There are many children who, though not orphans, are becoming vulnerable as a direct or indirect result of HIV and AIDS. When parents fall sick, particularly in poor families, children come under intense stress that may continue in different forms for the rest of their lives. They may be taken out of school to farmland or to take part in income-generating activities. They may become caregivers themselves or even head of households. In many cases, such children become increasingly vulnerable to malnutrition, ill-health, abuse and exploitation. There are psychosocial effects, under-researched but potentially very damaging, overriding these stresses, both in the short and long term.

This paper has three parts. First, we briefly review the evidence for the different aspects of vulnerability experienced by children affected by HIV and AIDS. We will build on the work by Foster and Williamson (2000), Birdthistle (2004), and recent material from additional sources. These include commissioned case studies from South Africa, Mozambique and Malawi (Adato *et al.* 2005; Arndt *et al.* 2005; Sharma 2005), a regional southern Africa study (Rivers *et al.* 2004) and relevant papers from the International Conference on HIV/AIDS and Food and Nutrition Security organized by the International Food Policy Research Institute (IFPRI) and held in Durban, South Africa in April 2005. Second, we draw upon the small but growing body of evidence of what works in addressing child vulnerability in the context of HIV and AIDS in order to generate some key principles for policy and programming. We conclude by highlighting research priorities. The objectives therefore are to:

1. Characterize the situation of orphans and other children (OVC) who are affected by HIV and AIDS with respect to who they are, and where and with whom they live;

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2. Use available evidence to describe the degree and nature of specific vulnerabilities that OVC experience or at risk of experiencing, including such outcomes as survival, health, nutritional status, educational enrolment and retention, psychosocial status and poverty, as well as any discrimination they may suffer in these different areas;
3. Review different approaches from the extended family upwards to responding to the situation of these children, leading to some basic recommendations on principles and options for response in different conditions;
4. Highlight challenges for research to fill important remaining gaps in knowledge.

PART I: CHARACTERIZING CHILD VULNERABILITY IN THE CONTEXT OF HIV/AIDS

Who is vulnerable?

Orphans are children who have lost one or both of their parents, and who are therefore deprived of the material, social and psychological support of one or more of their primary caregivers. It is hypothesized that this will result in lower levels of investment in their human capital such as schooling, clinic visits, care time and food access.

Combined with this potential drop-off in investment, orphans are thought to have a weaker voice in redressing discrimination. This combination of lower potential investment and weaker voice is considered to make orphans very vulnerable to other shocks and deprivations including food insecurity and malnutrition.

First, the scope of this review needs to be defined in terms of who is vulnerable and to what forms of deprivation. There are considerable differences in definitions of orphanhood; in fact, the word "orphan" is not readily translated in many sub-Saharan languages and cultures. The Joint United Nations Programme on HIV/AIDS (UNAIDS) defines an orphan as *"a child under 15 years of age who has lost their mother (maternal orphan) or both parents (double orphan) to AIDS"*. This definition, however, excludes paternal orphans, orphans aged 15-18, and non-AIDS orphans.

Affectedness can be defined demographically or socially. This paper will use a broad definition that goes well beyond strict orphanhood as defined above to include many other non-orphaned children who are likely to be affected by HIV and AIDS. The various subgroups are as follows:

1. Children who have lost one or both parents to AIDS (maternal, paternal and double orphans) wherever they live, including on the street ("biological orphans");
2. Children whose parents are alive but who live with relatives or non-relatives under strained capacity (often identified as "social orphans");
3. Children living in households with adult caregivers (parents or non-parents) or other siblings who are chronically ill, possibly due to HIV/AIDS.
4. Children who are HIV-positive or living with HIV and AIDS, some of whom may be orphans;
5. Children in poor households who are not orphaned but experience an adult death;
6. Children living with their parents in fostering households, which may have recently taken in an orphaned child.

The first two subgroups alone present a range of living arrangements (Table 1):

Table 1: Types of Child Residence Status

	Father alive, residing with child	**Father alive, not residing with child**	**Father dead**
Mother alive, residing with child	Both parents present	Absent father	Paternal orphan
Mother alive, not residing with child	Absent mother	Fostered (social orphans)	Paternal orphan, absent mother (fostered)
Mother dead	Maternal orphan	Maternal orphan, absent father (fostered)	Double orphan (fostered)

In many cases it is impossible to identify children orphaned by AIDS, at least based on survey data. Until recently, little survey-based empirical work has been undertaken on orphans since they tended to be ignored in household surveys. Few data sets, for example, have information on the reason for non-residence of mothers and fathers. Without information on whether or not non-resident parents are alive, it is not possible to distinguish orphans from children with absent parents. National Demographic and Health Surveys (DHS) data may permit filling out the nine cells in Table 1, but offer a very limited set of variables to explain the residence and mortality status of parents or the decision of a household to foster a child. Again, this complexity relates to the first two of the six categories of vulnerable groups only.

- *The pattern of orphan age distribution is fairly consistent across countries.*

Orphan prevalence exhibits an age-pattern related to the duration of exposure to the risk of losing a parent (Bicego *et al.,* 2003). Due to the long incubation period for HIV, infected adults may live for many years, resulting in an increased prevalence of orphaned children in later age cohorts. According to DHS 1997-2002 data for 40 sub-Saharan African nations, the proportion of orphans in different age groups is as follows: 0–1 years old (2%), 1–4 years old (13%), 5–9 years old (35%), and 10–14 years old (50%) (UNICEF, 2003). While statistics exist for the age distribution of orphans, there has been little parallel work in attempting to quantify the age distribution of children at the time that they *become* vulnerable.

- *Paternal orphans are more prevalent than maternal orphans.*

A higher reported prevalence of paternal than maternal orphans (see Table 2) has been attributed to women often leaving their children and returning to their natal home in cases of separation or divorce, resulting in a higher probability that the loss of a father will be reported than that of a mother. Further, men tend to remarry after the death of their wives and the children left behind by the first wife are considered to have both parents alive (Kamali *et al.,* 1996).

Table 2: Proportions of different types of orphanhood from selected studies in sub-Saharan Africa

Study location	% Maternal	% Paternal	% Double	Source
Uganda	26.3	72	1.7	Ntozi *et al.* (1999)
Western Uganda	27	60	13	Kamali *et al.* (1996)
Zimbabwe	13.6	81.8	4.5	Kamali *et al.* (1996)
Western Kenya	19.6	49.2	31.2	Nyambedha *et al.* (2003)
Study location	%Total Maternal	Total Paternal	Total Double	
Sub-Saharan Africa	6.2 million	7.8 million	Total Double 3.6 million	UNAIDS/UNICEF/USAID 2002

- *The geography of orphan (urban-rural) distribution is diverse.*

Orphans are clustered according to the context of HIV and AIDS in a given community or nation. DHS and UNICEF-Multiple Indicator Cluster Survey (MICS) data show far higher proportions of orphans in Namibia and Botswana living in rural areas, whereas in Ethiopia and Uganda, for example, the opposite is the case with a preponderance of urban-dwelling orphans (UNICEF 2003). Sharma (2005) finds the prevalence of orphans in Malawi to be higher in areas that have higher population densities.

Many orphans end up on the street. In Zimbabwe, Mawoneke *et al*. (2001) found half of the street children in two cities to be orphans, more than twice the proportion found in the general population. The main factors that led children to the street were poverty, a desire to be financially autonomous, ill treatment by parents or guardians, orphanhood, religious influence and overcrowding at home. The majority of double orphans (56%) and of maternal orphans (58%) lived on the street most of the time, while the majority of paternal orphans (68%) and of non-orphans (71%) lived at home or with a guardian. In another study in Zambia in 2002, the majority of street children in Lusaka were orphans – 22% double orphans, 26% paternal orphans, and 10% maternal orphans (CONCERN/UNICEF 2002).

Who does the caring

Most single orphans live with their surviving parent (Case, Hosegood and Lund, 2003). In their analysis of 28 countries, Ainsworth and Filmer (2002) found that paternal orphans in most of East Africa were much more likely to live with their mother than in West Africa and far fewer of those who lose their mother remain with their father. In Zambia, for example, only 40% of maternal orphans lived with their fathers, compared with 74% of non-orphans (Case, Hosegood and Lund, 2003). In Zimbabwe, 59% of the paternal orphans lived with their mother, but only 6% of the maternal orphans lived with their father (Mawoneke *et al.,* 2001). Surviving fathers are more likely than mothers to transfer responsibility of their children to others, particularly grandmothers. In an analysis of DHS data, double orphans have been found to be much more likely than other children to be in households headed by a grandparent (Bicego *et al*., 2003).

According to two South African studies, children in households affected by AIDS are more likely to migrate compared to other children (Hosegood and Ford, 2003; Adato *et al*., 2005). In Kenya, Yamano and Jayne (2004) found that older daughters commonly leave the household after the death of a male head, while younger children were more likely to leave the household after the death of a female head.

- *The vast majority of orphaned children live with extended family.*

Orphans may also live with unrelated foster families, in small group homes, children's villages, child-headed households and orphanages, or on the street (WFP, 2003). Most children, however, are still being cared for by the extended family.

Fostering of orphans by relatives is well attuned to the prevailing African socio-cultural milieu (Subbarao *et al*., 2001). In South Africa, for example, fosterage is not a new response to AIDS (Madhavan, 2004), although AIDS has stressed fostering patterns. There are two basic patterns of fosterage: *voluntary and crisis-led fostering.* Voluntary fosterage pertains to arrangements between biological and foster caregivers to raise the child, but is not a formal adoption, while crisis-led fostering occurs in response to the death of a biological parent or a major shock.

Fostering may also be undertaken when alternative support networks do not exist or are unavailable to affected-households. As networks continue to be stressed and weakened, the distribution and geography of orphans are likely to shift.

- *Which extended family members provide care?*

There are major differences between countries with regard to *who* within the family will assume primary caregiving responsibility. Grandmothers and aunts are the most frequent primary providers of orphans fostered by kin (Madhavan, 2004; Adato *et al*., 2005). In a study of Uganda (Gilborn *et al*., 2001), 42% of guardians were aunts/uncles, 45% were grandparents, 4%, step-parents and 5%, siblings.

Cultural norms for a particular community determine which side of the family will foster the child. For example, in a study on Uganda (Urassa *et al.,* 1997) caregivers were more commonly from the maternal side. In contrast, in polygamous communities of Western Kenya, the majority of orphaned children were be cared for within the patrilineal system, with maternal relatives playing a lesser role (Wandibba, and Aagaard-Hansen, 2001). In South Africa, a divergence from the protocol of patrilateral responsibility was found (Adato *et al.*, 2005). Several reasons were cited. Terminally ill mothers are often cared for by their families and their children then remain in the same household after their death. Second, many children do not maintain links with their fathers and/or fathers' relatives; fathers have often long ago disappeared. A third and less prevalent reason is that despite formal obligations of father's relatives, brothers' wives are not always welcoming of the children.

- *Many orphans are living with ageing family members.*

The old age of many primary caregivers has major implications for future support and livelihood. According to DHS data, throughout the 1990s in sub-Saharan Africa, orphans were much more likely than other children to be in households headed by a grandparent (Bicego *et al*., 2003). Data from South Africa, Zimbabwe and Malawi indicate that 65%, 62% and 50%, respectively, of children not living with their parents are living with their grandparents (UNICEF, 2003).

Orphans are often reported to be less likely to receive adequate care from elderly caregivers, who are less likely to work and provide the necessary support (Nyangara, 2003). While this assumption prevails, little research has been done on their competence to provide adequate care. For example, in their work on elderly caregiving, Nyambedha *et al.* (2003b) found that unfavourable macroeconomic trends, population growth and the meager returns of subsistence farming due to unreliable rainfall – not old age per se – were the major factors contributing to the difficulty of caregivers in ensuring adequate support. This is an important area for further research.

- *Orphans are often separated from their siblings.*

In a Zambian study, for example, it was found that 56% of orphans were likely to be separated from their siblings. Of these, 26% never see each other at all and 20% see each other only once a year (USAID/SCOPE/FHI 2001). Such separation is likely to have implications for the emotional well-being of a child as well as for their system of support, which may in turn affect their food and nutrition security. This latter link, however, has yet to be examined.

- *The proportion of child-headed households in communities is likely to increase significantly.*

A number of factors predispose to the establishment of child-headed households: rapid increase in the number of parental deaths; death of one or both parents; reluctance of relatives to foster orphans; lack of contact of relatives with children; death or sickness of a relative; presence of adolescents or older children able to care for younger children; children's preference to live in child-headed households; and the inheritance of residence by surviving children (Foster *et al.,* 1997).

In a study of child-headed households in Zimbabwe, (Foster *et al.,* 1997), in 88% of households the nearest relative did not want to care for the children, while in 32% of households, the children did not want to move to the relative's households or the relative to move in with them.

As expected, a higher percentage of orphans live in households headed by children compared to non-orphans (Nyangara, 2003). Again, more research is needed on these results with regard to food and nutrition security impacts and future policy options as the prevalence of child-headed households increases.

Aspects of vulnerability

Not every vulnerable child is an orphan and not all orphans are vulnerable. So what aspects of vulnerability should concern us most in the context of children and HIV and AIDS and what determines these outcomes?

It is important at the outset to keep sight of the fact that an increasing number of households and communities are struggling to respond to multiple, overlapping vulnerabilities and interacting processes of change. Certain types of household are particularly vulnerable to AIDS impacts and certain types of individuals within these households are particularly vulnerable. Moreover, vulnerability is not a static condition – it is enmeshed in a dynamic cycle and generated by exposure to change, the inability to respond to change, and the outcomes of these processes (Quinlan *et al,* 2005).

In the context of children affected by HIV/AIDS, this report focuses on the following aspects of vulnerability: means of survival, nutrition and health, education, poverty, as well as psychosocial and societal impacts. This broadly aligns with Birdthistle's (2004) useful categorization of pathways to vulnerability:

- *Biological*: The transmission of HIV from mother to child increases infant and child mortality at least up to the age of five. Lack of access to antiretroviral treatment and health care shortens the survival time of HIV-infected children. A mother's serious illness or death is linked to the illness and death of her young children, perhaps through the cessation of breastfeeding or inadequate feeding or care. A child's biological relatedness with his/her head of household seems to influence the educational outcomes of fostered children (Case, Paxson and Ableidinger, 2004).

- *Economic.* The loss of a prime-age adult (15-45 years of age), especially a father, will reduce household income and assets, deplete crop production while increasing expenditures on health care, funerals, and memorials, and increase the dependency ratio in the home. (Recent evidence of such impacts is provided in Gillespie and Kadiyala, 2005). Dissolution of households forces some orphans into poorer homes, while others

are turning to the street or paid labour that may be exploitative. Financial assistance provided by extended families and aid agencies is influencing the outcomes of orphans. Although orphans are often found in the poorest homes, household wealth, whether calculated as an absolute or relative measure, does not account for all of the differences with non-orphans, implying their needs are not simply financial.

- *Emotional*. For such a profoundly important aspect of a child's growth and development, this area is disturbingly under-researched (see below under "Psychosocial impacts").

Survival

- *Child mortality is highly associated with maternal HIV status in Sub-Saharan Africa*

In a particularly convincing study involving over 14,000 child-years of observation between 1989 and 2000 in 15 Ugandan villages, Nakiyingi *et al*. (2003) found child mortality risk to be more than four times greater among infants and nearly three times greater among children born of HIV seropositive versus seronegative mothers. Mortality declined rapidly with age and was higher among boys and children of teenage mothers. Longitudinal studies in Rakai District, Uganda and Kisesa, Tanzania found that newborns of HIV–infected mothers had more than twice the chance of dying than newborns of HIV-negative mothers (Sewankambo *et al*., 2000; Urassa *et al.* 2001). In a separate study in Malawi, a heightened risk of dying persisted at least up to five years or age, although the degree of risk declined with age (Crampin *et al.,* 2003). Child mortality was associated with the death of HIV-positive mothers but not of HIV-negative mothers or fathers. In the Kisesa cohort in Tanzania, child mortality risks were as high in the year preceding the mother's death as in the first year of orphanhood (Ng'weshemi *et al*., 2002).

Orphans are likely to be particularly susceptible to HIV infection. Controlling for wealth and other factors in a South African study, orphanhood was found to confer added risk for unsafe sexual behaviour (Hallman, 2004).

Nutrition and health status

In a meta-analysis of national nutrition and health surveys undertaken in sub-Saharan Africa over the last five years, orphan children, however defined, were not worse off in terms of anthropometry than other children (Rivers *et al.,* 2004) – a finding that held after adjusting for age differences, taking into account the presence of surviving parents in the household, and after stratifying for place of residence and sex of the head of household.

In a Malawian study (Taha *et al.*, 2000), among maternal orphans the lack of association between either the mothers' HIV status or the child's orphanhood and their risk of stunting, wasting, or reported ill health was explained as being due to a lack of discrimination on the part of fostering extended families. An earlier and smaller cross-sectional study in the country also did not find significant differences between the nutritional status of orphans cared for by guardians in extended families and non-orphans (Panpanich *et al*., 1999).

Yet, in a Tanzanian study, orphaned children were more likely to be stunted (Lundberg and Over, 2000; Ainsworth and Semali, 2000), with the most severely affected being children in the poorest households, those with uneducated parents and those with least access to health care. Foster and Williamson (2000) have also shown that orphans in Tanzania and Zambia were more likely to be stunted but no more likely to be wasted than non-orphans. In Uganda, orphans' health and

nutritional status was worse, and their use of public services much lower than that of non-orphans (Deininger *et al.,* 2003).

- *The type of orphanhood matters.*

It is generally held that maternal orphans are at greater risk for health problems due to the loss of their primary caregiver. In one study, however, children who had lost a father were more likely to be malnourished than non-orphans (Lindblade *et al.,* 2003). Ntozi *et al.* (1999) found that surviving fathers in Uganda provide more care than mothers, *"perhaps because the fathers have more means, and the husband's relatives often deny the widows the opportunity to look after the orphans."* Further, surviving fathers had more decision-making power than women. In polygamous households, the death of a father can lead to many more orphans than the death of a mother, and thus may have a greater negative impact on more children and more livelihoods (du Guerny, 1998).

In Tanzania, Ainsworth and Semali (2000) show that the death of the mother was associated with an average decline of one standard deviation in child height for age between 1991-1994, while a paternal death was associated with a decline of one-third of a standard deviation. The impact of maternal orphanhood is severe regardless of household assets, while the impact on paternal orphans is felt only among poor households.

- *Evidence of the impact of orphanhood on children's health and nutritional status is mixed.*

The nutritional dimension of child vulnerability is variable, but more detailed research is needed to distinguish the various drivers and pathways of interaction in different socio-economic contexts and at different stages of the epidemic.

It is important to identify vulnerable children, especially children of people living with HIV and AIDS (PLHA), not just orphans. In a Ugandan study, for example, 15% of children whose parents were infected with HIV and 19% of orphans self-reported as being in poor or very poor health. One-third of older children living with an HIV-positive adult (34%) and of older orphans (31%) stated that *there were some days when they do not get enough to eat* (Gilborn *et al.*, 2001). These and other data reinforce the importance of identifying vulnerable children, especially children of PLHA, not just orphans. When a parent falls ill, children often shoulder new responsibilities including domestic chores such as cooking, cleaning, carrying water and laundry, caregiving activities such as feeding, bathing, toileting, giving medication and accompanying relatives for treatment, agricultural or income-generating activities and childcare duties (Foster and Williamson 2000). These extra responsibilities have likely implications for the child's schooling as well (see below under "Educational Status").

In a study of Zaire, for example, there was no significant difference between orphans and non-orphans regarding frequency of eating breakfast (Foster and Williamson 2000). In Uganda, 69% of guardians studied felt that they were able to feed the children adequately (Gilborn *et al.* 2001). In Kenya, Lindblade *et al.* (2003) also found that there were no significant differences in key health indicators between orphans and non-orphans.

Educational status

Many studies have reported the negative impacts of HIV/AIDS on children's schooling, primarily using indicators of enrolment, attendance and retention.

- *Educational impacts start when a parent becomes ill, and are most severe for poor households.*

Although few studies have measured effects on children before their parents die, two do shed some light. The first study in Uganda indicated that the education of adolescents living with and caring for a terminally sick parent may suffer more than that of fostered orphans (Gilborn *et al*, 2001). In a second study in Kenya, (Yamano and Jayne, 2005) adult mortality negatively affected schooling in the period directly before mortality occurred – most likely, they surmise, because children are sharing the burden of caregiving.

Yamano and Jayne (2005) found the negative impact of adult mortality on child school attendance in Kenya to be more severe in poor households, as did Nampanya-Serpell (2000) in urban but not rural areas of Zambia. Deininger *et al.* (2003), in an analysis of a panel data set of 1,300 households included in surveys conducted in 1992 and 2000, show that foster children were at a distinctive disadvantage in both primary and secondary school attendance before the introduction of the Universal Primary Education program in Uganda.

- *Orphans fostered by distant relatives or unrelated caregivers are at risk.*

In a recent study using 19 Demographic and Health Surveys conducted between 1992 and 2000 (Case, Paxson and Ableidinger, 2004) the impact of orphanhood on children's school enrollment is examined in ten sub-Saharan African countries. Poorer children, whether orphans or not, are less likely to attend school than other children. Orphans are less likely to be enrolled than are non-orphans with whom they live. This is largely explained, the authors suggest, by the greater tendency of orphans to live with distant relatives or unrelated caregivers who are more likely than extended family to discriminate against the orphaned child. In a South African case study (Adato *et al.*, 2005), there was no significant evidence of educational disadvantage among orphans, although the authors speculate, following Case, Paxson and Ableidinger (2004) that this may be because most fostering households in their study area were close kin.

In Mozambique, a study uncovered discrimination against children that are not direct biological descendants of the household head in the intra-household allocation of resources (Arndt *et al*., 2005). At each level of analysis (national, rural and urban), discrimination occurred with respect to expenditure on at least one resource in each of the three age groups identified.

Case, Paxson and Ableidinger (2004) also found the effects of orphanhood on education to increase with age as did Sharma (2005) in Malawi – and found no evidence that female orphans are disadvantaged relative to male orphans.

- *Maternal orphans and double orphans are particularly vulnerable to inadequate care.*

Analysing longitudinal data from KwaZulu Natal, Case and Ardington (2004) find the loss of a child's mother to be a strong indicator of children's poor schooling outcomes. Maternal orphans are significantly less likely to be enrolled in school, tend to complete significantly fewer years of schooling, and on average, less money is spent on their education. The primary impact here is not poverty per se, but a lack of care manifested in reduced educational attainment and enrollment compared to paternal orphans (Bicego *et al*., 2003; Case, Hosegood and Lund, 2003; Nyamukapa *et al*., 2003), the effects of which are independent of household socio-economic status.

The loss of a father is also correlated with children's poor educational outcomes, but this is much more likely to be driven by poverty. Paternal orphans tend to live in poorer households than non-

orphaned children (Case, Hosegood and Lund, 2003; Nyamukapa et al., 2003). Although they do not reside in households that are poorer than non-orphans, double orphans are particularly at risk of not being enrolled or being pulled out of school (Bicego *et al*., 2003). They are also found disproportionately in rural and female, elderly-, and adolescent-headed households and living on the street.

General poverty remains the main cause of low enrolment and retention in many situations. In a study of rural Zimbabwe (Senefeld and Polsky, 2005), 12% of boys and 15% of girls had recently left school although the inability of 44% of the drop-outs to pay school fees was found to be unrelated to household HIV or orphan status.

- *Schooling is often the first to be affected.*

For many households, food requirements are more easily maintained than health care or schooling (UNICEF 2003). In two studies of households with orphans in Tanzania and Burkina Faso, it was found that 21% and 22% of households respectively could not meet food needs, while 41% and 25% could not meet their schooling needs. In Uganda, Ntozi *et al*. (1999) found that the main problems facing orphans were inadequate financial support, lack of parental care and mistreatment. Lack of food and/or issues of food security were not noted. A study in Kenya found that 84% of households mentioned schooling problems (i.e. buying school books, uniforms, affording time for school rather than working at home, etc) while only 48% reported a lack of food (Nyambedha *et al.,* 2003a). A study in Uganda found that the main problems among Ugandan orphans were: inadequate shelter; the inability to pay school fees and buy supplies; lack of bedding, clothing and medical care; and the burden of having to care for younger siblings (Gilborn *et al.,* 2001). Nowhere in these results were inadequate food and nutrition mentioned.

Poverty and household food insecurity

- *Paternal orphans are likely to be from poorer households.*

Paternal orphans tend to live in poorer households than maternal orphans, double orphans or non-orphans, according to analysis of DHS data (Case, Hosegood and Lund, 2003). Households containing either maternal or double orphans were not poorer than those of non-orphans. According to an analysis of DHS data from five countries (Zimbabwe, Kenya, Tanzania, Ghana, and Niger), orphans were not found to live in poorer households than non-orphans in general, although this did vary somewhat from country to country (Bicego *et al*., 2003).

Findings from a community-based baseline study in eastern Zimbabwe (Nyamukapa *et al.,* 2003) concurred with those of Case, Hosegood and Lund (2003). Paternal orphans were significantly worse off in terms of ownership of household assets. Orphans were also more likely than other children to be found living with household heads who had received no school education and/or who were currently unemployed, and were found disproportionately in rural, female-, elderly-, and adolescent-headed households.

In the Kisesa Community Study in Tanzania (Urassa *et al.,* 1997), households with orphans did not have a lower economic status in terms of off-farm income, household assets and physical structure of the house. Orphans seemed to be absorbed by households already containing children, making the households larger and the dependency ratio less favourable. They were also more likely to be female-headed.

Other studies in sub-Saharan Africa have shown that fostering households are not necessarily among the poorest in a community (Seaman and Petty, 2005; Senefeld and Polsky, 2005).

- *Households fostering more than one orphan are more likely to be food-insecure.*

There is some evidence, nevertheless, of the increasing burden of orphan care becoming manifest in food security indicators. The Rivers *et al.* (2004) DHS analysis found that 38% of households with more than one orphan were classified as "food insecure with child hunger", significantly more than households with only one orphan (7 %)or no orphans (13 %). A much larger percentage of orphans live in households that are classified as "food insecure with child hunger", and those with chronically sick members were also found to be more food insecure. While households can manage to absorb one orphan without being impacted significantly, they appear unable to take on more orphans without affecting their livelihood. As mortality rates increase and the population of orphans continues to rise, more and more households will be faced with the decision to foster more than one orphan or leave him/her to fend for him/herself.

Psychosocial impacts

Psychosocial impacts of HIV and AIDS on children are likely to be profoundly important, but very difficult to measure. How to measure the effects of losing a role model and the love and respect of a parent? What is the emotional impact of seeing one's mother or father slowly die? And how does this manifest itself in other areas such as educational attainment, health and socialization?

- *Many children are depressed and afraid.*

The little research available depicts pervasive anxiety, sadness, fear, and hopelessness among children and adolescents during their parents' AIDS-related illness and death, and subsequently in orphanhood. Studies consistently detect depressive, internalizing problems among orphans with little evidence of anti-social behaviour such as lying, stealing or hostility. As for risk and protective factors, girls and young adolescents (e.g. 10-14 year olds) may be particularly distressed. Staying in school and living with a surviving parent or adult relative seemed to help some children endure the trauma, according to Birdthistle's review (2004) of the literature. There is an urgent need for research aimed at elucidating emotional impacts by age, type of orphan and living arrangements.

Research also indicates that an HIV-infected parent's emotional well-being influences the children's welfare. Fear, denial and guilt can influence a parent's decisions about disclosing his/her HIV status, communicating to children about HIV and AIDS, and planning for his/her children's future (Birdthistle, 2004; Adato *et al.,* 2005)

Given that many children are becoming caregivers themselves, more research is also needed into understanding both the negative and positive impacts that such responsibility has on children, the needs of children as caregivers, and the ways in which disruptions in schooling can be minimized (Foster and Williamson, 2000).

Societal impacts

The predominant narrative on the potential long-term societal impacts of widespread orphaning of children posits that high AIDS mortality rates will produce a large number of poorly socialized

orphans who will be ill-equipped to act as responsible citizens, thus eventually precipitating a breakdown in the social fabric of a country, and cumulatively the region.

Bray (2003) argues, however, that these apocalyptic predictions are unfounded. While focusing on the orphans right "fit" within societal boundaries, much less attention has been directed to the multiple layers of social, economic and psychological disadvantage that not only affect orphan children, but families and communities as a whole. Such multi-layered vulnerability is not unique to children affected by AIDS – the socio-economic disadvantage they endure may be in a similar order of magnitude to the marginalization suffered by other children from discrimination because of their race, caste, ethnicity, poverty, gender and/or the living standards that they might have been adopted in response to rejection and poverty. None of these disadvantaged children individually have prompted a social breakdown and there is no evidence that those affected by HIV and AIDS would be different. Bray suggests that a more nuanced and multi-faceted approach is necessary to assist orphan children in coping with circumstances that are a direct result of the impact of HIV/AIDS in their lives.

PART II: PROTECTING CHILDREN AFFECTED BY HIV/AIDS

Knowledge and experience in orphan care is relatively thin on the ground compared to prevention, care and treatment, but it is now growing.

Drawing on the lessons learned as this experience grows, an important multi-organizational framework for protection, care and support of orphans and vulnerable children has recently been developed (UNAIDS/UNICEF, 2004).

The framework is holistic, shifting from single vertically implemented interventions to a multi-pronged approach that focuses on strengthening the capacities of families, communities and children themselves, supported by appropriate policies and services, to meet the needs of affected children. The key strategies are to:

- strengthen the capacity of families, rather than affected individuals, to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support;
- mobilize and support community-based responses;
- ensure access for orphans and vulnerable children to essential services, including education, health care and birth registration;
- ensure that governments protect the most vulnerable children through improved policy and legislation and by channelling resources to families and communities;
- raise awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV and AIDS.

Box 1: Extract from United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS (2001)

The Declaration states what governments have pledged to do – both individually and in collaboration with others in international and regional partnerships, and with the support of civil society - to reverse the epidemic. It includes the following section (paragraphs 65-67).

Children orphaned and affected by HIV/AIDS need special assistance

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

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

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

Source: UNGASS, 2001

Strengthening the capacity of families

The starting point for ensuring the adequate care of children affected by HIV/AIDS is the extended family and kin group. The fostering of children by relatives has thus far been the most prevalent practice in sub-Saharan Africa and seems to be the most effective and desirable first line of response (Deininger *et al.,* 2003). A South African study states that as long as potential caregivers are able to garner support through government grants, as well as access to counseling services, the extended family safety net seems capable of capturing many of the children affected by HIV and AIDS (Adato *et al.,* 2005).

The primary obstacles to the provision of adequate care of orphans are thus not sociological but economic. Fostering households will need a wide range of material and non-material support systems to help them cope economically and socially (Adato *et al.,* 2005). These needs will only be exacerbated by the rapidly increasing numbers of orphans that will put this traditional system under severe stress over time.

Any approach to strengthening the capacity of the extended family to cope with the extra burden of an orphaned child needs to be cognizant of any other stresses and sources of vulnerability that may be simultaneously affecting the household and the child.

Strengthening community capacity

Given the stigma still associated with HIV and AIDS even after intensive prevention campaigns, it is impossible to reach most individuals or families affected by HIV and AIDS via programmes specifically targeted to them. Such targeting also faces the ethical issue of singling out those whose losses are tied to a specific disease. Interventions are required that address the needs of vulnerable groups, families, and individuals in a much more holistic way, based on a proper needs assessment.

Service delivery approaches through the public sector or NGOs may work in urban and peri-urban areas, but are costly and hard to scale for widely dispersed rural populations. Community-driven approaches that build on existing community structures such as self-help groups, women's

groups, and church groups, offer great potential (Nyambedha, Wandibba, and Aagaard-Hansen, 2001). Based on their research in Tanzania, Urassa *et al*. (1997) have suggested that as the number of orphans increases, communities will not have to develop radically different coping mechanisms. The challenge, and probably the only feasible intervention, they argue, is to develop community-based support systems that focus on the most vulnerable households and extended families, using only limited external support. Citing experience from community-driven approaches to other development challenges, Binswanger *et al.* (2005) concur – communities could be provided with the training, facilitation and financial means to manage the basic social protection activities of the vulnerable families in their midst, with such efforts being coordinated at the local level.

Community-driven development has unique advantages: it is well placed to respond to the demands for local information and knowledge, resulting in locally appropriate responses. Such local knowledge, rather than generic standards imposed from elsewhere, better addresses questions on who is vulnerable and what the major forms of vulnerability are. Externally derived responses may be viewed by community members as inappropriate if they undermine existing coping mechanisms and may not be sustainable for this and other reasons. Intervention planning must therefore take into account existing norms and practices and seek to strengthen family and community capacities to protect and care for vulnerable children.

Community-driven development is designed to maximize community capacity and involvement, but this does not imply that communities would be left without support. Though many community initiatives are established without external facilitation, they can be strengthened by involving external allies. Partnerships between community groups and outside organizations offer great potential for developing sustainable, effective and scaled-up responses to the needs of children affected by HIV and AIDS (Foster, 2002).

Lessons can be gleaned from the growing literature on community-driven development (see Gillespie 2004). Box 2 provides some country-level examples of community-led interventions for responding to child vulnerability to AIDS, many of which are supported and facilitated by local NGOs. (Additional case studies are provided in the annex.)

Although it is difficult to come up with cost norms to compare different types of interventions owing to the different types of assistance provided and the various scales of activity, there is evidence that community driven interventions, including extended household networks, are the most cost-effective form of intervention for caring for orphans and vulnerable children (Subbarao and Coury, 2004). In contrast, those based on boarding schemes such as orphanages are regarded as costly and non-sustainable.

Little work, however, has been done in detailing specific strategies and interventions, which would make such an approach feasible and sustainable for institutions already under increased stress and diminishing resource capacity.

Box 2: Examples of Community-Driven Approaches

Scaling-up HIV/AIDS Interventions Through Expanded Partnerships (STEPs) in Malawi

STEPs is a community-driven approach to scaling up HIV/AIDS interventions in Malawi. Supported by USAID and Save the Children US, STEPs started in 1995 (then called Community-based Options for Protection and Empowerment) as a service-delivery program in one district in Malawi, to assist children

affected by HIV/AIDS. Through evaluations, SC realized such an approach was unsustainable, cost-ineffective and not scalable. Based on the recommendations of the evaluations and field experience, the programme revitalized the dormant decentralized AIDS committees (at district, community and village levels) and their technical sub-committees, with the support of the National AIDS Commission (NAC), in the Namwera community in Mangochi to mobilize collective action to combat the epidemic.

Based on the positive experience in Namwera, the program changed its initial strategy to that of an external change agent, assisting communities with community mobilization and capacity building so that communities become empowered to act collectively to address their own problems. Village AIDS Committees (VACs) identify the vulnerable and plan responses on the basis of the nature and magnitude of vulnerability within the villages, the needs of the vulnerable, and the capacity within the villages to respond. They also monitor the activities and mobilize resources. Due to the crosscutting nature of the needs of the most affected communities, the program became truly multisectoral with activities along the continuum of prevention, care, support and mitigation. STEPs has also influenced national policies related to HIV and AIDS and children. Through partnerships with and training of other NGOs/CBOs in the program approach of community mobilization and collective action facilitation, STEPs and similar models aim to cover 75% of Malawi's population (Kadiyala, 2004).

Community-based childcare centres in Nthondo, Malawi

World Vision assisted Nthondo community members in pulling together their resources and donating their time and effort to establish and run ten childcare centres with 335 boys and 326 girls. Local leaders have also donated some of their farmland to establish community gardens. In collaboration with the local leaders, school volunteers mobilize people in the surrounding villages to work on the community gardens. Produce from the gardens is used to feed the children in the centres, with leftover produce sold at the local market to help meet running costs.

Indlunkhulu in Swaziland

"Indlunkhulu" refers to the provision of food from the chief's fields for members of the community that are unable to support themselves. In Swazi law and custom, chiefs are responsible for the welfare of orphans within their area. This provides an existing basis on which to build a sustainable mechanism for the delivery of food to orphans and vulnerable children. The implementing agency for the Indlunkhulu project is the Ministry of Agriculture and Cooperatives. Through the Ministry, the National Emergency Response Committee on HIV/AIDS (NERCHA) provided the initial agricultural inputs for the Indlunkhulu fields. It is the responsibility of community members to plough and tend the crop grown on this land. OVC also assist in tilling the fields, giving them practical experience in subsistence farming, helping them to develop skills for later on in life. The Indlunkhulu fields are intended to provide a sustainable source of food for them.

Source: Gillespie and Kadiyala, 2005

Aligning sectoral support

Ultimately, unless households and communities are given the support they need to ensure the adequate care of orphans, the livelihoods of both households and children may deteriorate. Sectoral policy thus needs to be much more proactively geared to assisting households in managing this increased burden and providing other options where this capacity is exceeded. This section reviews the potential contributions of different sectors to such support.

In view of the documented educational disadvantage of orphans, schooling support is critically important (Nyambedha, Wandibba, and Aagaard-Hansen, 2001). Food-for-education holds great promise. School feeding programs have the potential to provide a double positive impact in

helping meet both educational as well as nutritional requirements. The link between education, food security and nutrition is not direct, but is very significant (Smith and Haddad 2000) – children who are fed in schools are more likely to be in schools, more likely to stay in school, and being less hungry, are better able to learn in schools. As educated individuals their future socio-economic prospects and those of their future children are also enhanced. One additional benefit is that HIV prevention education may also be delivered at school (Ainsworth and Filmer, 2002). The World Bank has estimated that the cheapest alternative for recurrent support to orphans is to provide them with schooling and nutritional supplements (Deininger *et al.,* 2003).

Support for, or the waivering of, school fees may thus be a viable option towards positive intervention, as well as providing incentives for children to go to school and stay there through school feeding. Deininger *et al.* (2003) showed that after the adoption of Universal Primary Education in Uganda, foster children were no longer disadvantaged with respect to access to education. In contrast, in the absence of proactive policies, access of young foster children to health services worsened over time. In Zimbabwe, school feeding keeps children in school: among food insecure households, 25% of children dropped out of "non-feeding" schools in the previous year, as compared to 15% where school feeding was in place (SADC, 2003). Other recommendations for strengthening educational sector support for children affected by HIV and AIDS include channelling funds from debt relief programs to schools to decrease fees and increase enrollment (Bhargava and Bigombe, 2003).

Educational investments for poor households in general – and not just households with orphans and vulnerable children – would aid in assuaging the financial burden of sending children to school. But it is important that policies aimed to support education of orphaned children be "incentive-compatible" with fostering households. In the absence of such compatibility, resources and services directed to orphans may simply be commandeered by others. In his study in Malawi, Sharma (2005) found that targeting food transfers to households with vulnerable children was not a problem when community managed. Food aid programs are quite important in upholding education levels of orphans since it is exactly during crisis times that children are pulled out of school and placed on the labour market to augment family income. However, the most challenging link in reaching out to orphans was ascertaining that resources received by the household actually trickle down to the orphans. Research has shown that due to existing intra-household discrimination, policies directed towards orphans are needed to correct the bias against them (Case, Hosegood and Lund, 2003), as discussed in "Policy and Principles" below.

In Tanzania, Ainsworth and Semali (2000) found that immunization against measles, oral rehydration therapy and increasing access to health care can disproportionately improve health outcomes among poorest children, and within that group, particularly among children affected by adult mortality.

The World Food Programme (2002) has outlined a number of policy interventions aimed at food and nutritional support for OVC, including the linking up of food aid and home-based care programmes, and food-for-training opportunities for older OVC, as well as school feeding programmes at both elementary and pre-school levels to alleviate short-term hunger and provide a better learning environment.

South Africa is the only country in the region that has a program of conditional cash transfers to eligible households, with two main grants, the Foster Care Grant and the Child Care Grant. Valuable economic support has been provided to households that were able to access them (Adato *et al.* 2005). Yet few households actually receive these grants – less than 2% of eligible foster households were receiving the Foster Care Grant at the time of study due to significant hurdles

and disincentives to eligible households including a lack of awareness of the grants, overly bureaucratic application procedures, long waiting periods, corruption and stigma. The criterion of both parents having died also remains a barrier to many maternal orphans whose fathers were not present in the household.

Providing psychosocial support

As a rule, programs to help vulnerable children have focused on material needs, followed by education and children's skills, but very few adequately address the social and psychological needs of affected children – just as little research has sought to document such impacts. Comprehensive care and support programs should include policies and laws for the protection of orphans and vulnerable children, medical care, nutritional support, clinical health services and home-based care, socio economic support, psychological support, education and approaches based on human rights.

Given that many children are becoming caregivers, there is an urgent need to strengthen the psychosocial support children receive so that they may be able to assume these responsibilities effectively and with minimal consequences to their own well-being. HIV education and life skills training at school can reap positive effects and work to better adjust children to the realities at home (Adato *et al.*, 2005).

There is also a critical need for a comprehensive counselling programme. Visits of AIDS-affected households, often by volunteers, is a pivotal expression of community solidarity. Where this is under way, visits are usually conducted by village women who volunteer their time and energy to counsel families and try to assist them in meeting their material needs (Foster, 2002). Despite its importance, however, little attention has been given to volunteer visits, either within community initiatives or those supported by the state. For example, Adato *et al.* (2005) found very few counselling services in three provinces of their South African study.

A particular priority group for psychosocial support are children in child-headed households. These children are highly vulnerable and may be extremely distressed. Specialized support services are needed, particularly for those dedicated community care workers and other adults in the community to oversee these children.

Policy and program principles

Drawing upon this limited but growing evidence base, some key emerging principles for orienting policy in the context of increasing child vulnerability are highlighted here.

- *The wellbeing of children affected by HIV and AIDS is closely tied to issues of poverty and resource distribution.*

The orphan problem needs to be considered in the context of poverty. High dependency ratios and low incomes are common in many households, and the main reason for households not taking in an orphaned child was poverty (Urassa *et al.* 1997; Nyambedha, Wandibba, and Aagaard-Hansen 2001; Madhavan, 2004). A lack of participation by the wider extended family kin network in feeding orphans was attributed to a lack of food (Nyambedha *et al*, 2003a. Thus, when thinking about mitigation strategies and policy targeting orphans and vulnerable children, there is a need to focus on poverty alleviation for those households that are intact because if they have the capacity, they will take in orphans and will usually care for them effectively. Communities do not need

education in orphan care but the financial capacity to implement the strategies they traditionally possess.

- *View poverty holistically, but also through the eyes of a child*

Mitigation strategies and interventions that bolster the capacity of communities and households will usually also benefit resident children. As children tend not to have a voice in their design, an "OVC lens" may be a useful tool to correct any discrimination found in households or to address issues of stigma at the community level.

Such a perspective would entail a checklist of key questions that address how traditional mitigation strategies affect the lives and livelihoods of orphans and vulnerable children. It would also allow policy-makers to formulate specific strategies to ensure that children affected by AIDS receive adequate care and resources– while understanding that children are part of a greater unit and that solutions need as far as possible to protect the livelihood of the entire family.

Formulating a mutually beneficial, incentive-compatible strategy is thus the goal. For example, a school feeding program is likely to directly benefit the nutrition of the orphan and would also provide a transfer to the household. Further, bolstering volunteer visiting programs would provide greater support for affected households as well as allowing members of the community to watch over children to ensure that no exploitation or abuse takes place. These are just two examples of strategies that would be mutually beneficial to both OVC directly and the households in which they live.

- *Build from the base to ensure local relevance and sustainability.*

An overriding policy and programming principle is to build progressively from the base, while ensuring a sectoral environment that is conducive to resilience. The extended family needs to be supported in the context of the community and an enabling and supportive sectoral policy. The focus is thus on maximizing existing household and community *capacity* and augmenting such capacity by external support from governments and NGOs. Prior to designing new intervention assessments, it is necessary to take into consideration the vulnerable child's perspective (an "OVC lens") in order to determine the limits of caring capacity of pre-existing networks in terms of health, food and housing, among others.

There is thus no "one-size-fits-all" approach that applies across countries or even within countries (Subbarao and Coury, 2004; Richter and Swart-Kruger, 1995). The context-specificity of child vulnerability requires that any intervention be carefully tailored and implemented within these children's social, cultural and economic environments.

- *View the OVC challenge as a multisectoral development opportunity.*

Just as the vulnerability of children is embedded within issues of household and community vulnerability and poverty, so should responses, as far as possible, be aimed at tackling underlying causes of such vulnerability. Clearly, short-term responses aimed at meeting critical immediate needs are required in certain situations. But in general, the approach should be one of maximizing developmental opportunities.

And just as there are likely to be multiple sources of child vulnerability, so should multisectoral solutions be sought. Multisectoral mainstreaming may be facilitated by applying an OVC lens to different sectoral policies and programs. In so doing, stigma may be reduced as the issue becomes

more central and the organizational scale of response also grows. In their recent review, Gavian *et al.* (2005) suggest that the 2004 consensus framework for the protection, care and support of OVC (UNAIDS/UNICEF, 2004) is the best current example of multisectoralism applied to a specific target population in the context of HIV/AIDS.

Box 3: Multisectoral OVC Programming in Malawi

The multisectoral national orphan program of Malawi integrated orphan care into already established structures such as AIDS committees. The National Task Force on Orphans ensured implementation of OVC policies and led to the development of the Malawi Programme in April 1996. With the collaborative effort of 47 NGOs, OVC assistance consisted of counselling, foster care, relief activities (food, shelter, and clothing), educational services, loan assistance, training and income-generating activities. A reported strength of the program is the strategy for advocacy – four posters illustrated different aspects of orphans, three "jingles" were broadcasted daily, and documentary films were created to promote the cause. By 1998, the Malawi Programme had identified and registered 173,000 orphans, 44,000 of whom received some sort of assistance, while another 14,000 received maintenance assistance

Source: Kalemba, 1998

- *Scaling up*

Considering the magnitude and increasingly worsening situation of children affected by HIV and AIDS in sub-Saharan Africa, the current response remains woefully inadequate. Even in one of the more progressive countries, Uganda, the entirety of efforts by NGOs, governments and donors thus far reaches only 5% of the 1.7 million orphans in the country.

In the most developed social welfare systems in the continent – South Africa – less than 2% of eligible households in one study area are accessing cash grants to which they are entitled (Adato *et al.,* 2005). Most support services in the country – whether provided by government, non-governmental, faith-based or community-based organizations -– are small-scale, piecemeal, ad hoc and uncoordinated.

Multisectoral approaches are one form of organizational scaling up because they increase the breadth of sectoral involvement. But governments and other institutions should also facilitate upscaling by encouraging and enabling communities to tap into local latent capacity e.g. unemployed or underemployed youth. Mass training and orientation of community-level volunteers as facilitators and change agents offer great promise. Investing in local institutions through support to decentralization could lead to more appropriate community-led responses to AIDS, thus obviating personnel constraints experienced in scaling up vertical programs. The experience of STEPs in Malawi is relevant here too (see Box 2).

To support such approaches, donors need to alter their time horizons and be more flexible. The World Bank Multi-Country AIDS Program (MAP) for Africa is one example (Binswanger *et al.,* 2005). With over $1 billion approved funding in over 34 countries, MAP adopts the following principles:

- Empower stakeholders with funding and decision-making authority.
- Involve actors at all levels, from individuals and villages to regions and central authorities.
- Provide support in the public and private sectors and in civil society.

- Encompass all sectors and the full range of HIV/AIDS prevention, care and support, and mitigation activities.

A recent interim review by the World Bank suggested that implementation experience had been mixed. Sectoral components were often disappointing but *"community-based and targeted interventions managed by civil society organizations and visited by the review team were often inspiring"* (World Bank *et al*., 2004:16).

PART III: RESEARCH CHALLENGES AND PRIORITIES

- *Identify and define the most vulnerable children affected by HIV and AIDS*

In trying to locate the most vulnerable children, we need to consider how HIV and AIDS intersects and interacts with other sources of vulnerability. In this way, we go beyond identifying *who* is vulnerable to better understand *why* households or certain individuals in these households are becoming vulnerable. Conversely, why are certain households or individuals more resilient than others in similar situations? And what does all this imply for vulnerability monitoring systems?

Discrepancies in estimated numbers of orphans, reflecting different definitions, still constrain policy and programming. Estimates for Uganda, for example, range from around 1 million (UNAIDS) to nearly 2.5 million (USAID). Communities' estimations may also differ. Such conflicts may result in a top-down approach to programmes that discourages community-led interventions. Externally imposed definitions may lead to complex targeting modalities that are open to abuse (Phiri and Webb, 2002).

More work also needs to be done in developing approaches to identify children made vulnerable by HIV and AIDS. A first step may be to investigate the circumstances or situations in which children find themselves disadvantaged (Deininger *et al.,* 2003). Ultimately, criteria for defining child vulnerability need to be much broader than simple orphanhood, taking into account food, shelter, clothing, who the head of household is, type of orphanhood, and whether the child is attending school. Foster's (2002) work on community responses to the OVC situation highlights the importance of consensus-based decision-making by which the community as a whole works to identify the most vulnerable children in the community. In order to begin to understand the complexities of child vulnerability due to HIV and AIDS, external agencies must build partnerships with communities who are already working to identify vulnerable children. More research is needed in the area of identification to establish appropriate and sustainable intervention policies.

Researchers must work harder to identify the most vulnerable, for example, by following subjects who have migrated out of original study areas, because affected children are more likely to migrate. They should make greater efforts in tracking the members of dissolved or relocated households, because affected households are more likely to dissolve. Further, they should sample broader populations including institutionalized, street and migrant youth and adolescent-headed households, because children affected by AIDS are disproportionately represented in such groups. Research is needed in a wider group of countries and in-country contexts. Quantitative and qualitative data need to be linked and more interdisciplinary research undertaken (Birdthistle, 2004).

There are two other important issues here regarding identification of the most vulnerable children affected by AIDS. First, since the DHS procedures require that an adult be available for interviewing, child-headed households have largely been undercounted in surveys and censuses (Bicego *et al.*, 2003) and are thus underrepresented in research and policy formulation. Second, there has been little research on the gender-disaggregation of child vulnerability in the context of HIV/AIDS. Male and female OVC may likely have different requirements and may be at different risks concerning sexual abuse, exploitation and food discrimination, among others. Understanding gender's role in how households absorb orphans and how they are cared for may assist in forming strategies on intervention policies.

- *Keep track of the dynamics, levels and types of vulnerability.*

In order to organize and implement external support, research must not only garner quantitative analysis on the numbers of children affected by HIV and AIDS, but also seek to understand the processes, trajectories and pathways through which a child *becomes* vulnerable.

Research in recent years (reviewed in Gillespie and Kadiyala, 2005) has highlighted the correlations between HIV and AIDS, decreased capacity for response and food and nutrition insecurity. While these linkages are being clarified in research that predominantly uses the household as the unit of measurement, intra-household dynamics, and especially impacts on vulnerable children, remain relatively hidden.

In addition, community-level impacts of high rates of child orphaning are under-researched. The capacity of communities to respond effectively needs to be measured before it can be effectively strengthened. The starting point should be to review existing tools and protocols for assessing community capacity (e.g. Gillespie, 2001).

While community responses may be the most appropriate, their feasibility and efficacy may decline as numbers of orphans continue to rise. It will be up to future research to identify how these trends will play out, and how exactly community coping strategies can be bolstered in order to ensure adequate food security and nutrition for orphans and other vulnerable children.

- *Expand research on psychosocial impacts and responses*

There is a major gap in knowledge of the psychosocial impacts of HIV/AIDS on children and the options that may be made available for responding to these impacts.

The linked issues of parental disclosure of HIV status to children and their planning for their children's future are virtually unresearched. The South African case study by Adato *et al.* (2005) is the first of its kind in this area. There is a tendency in the prevailing discourse to assume that children go from being vulnerable to orphanhood without any action taken by parents. The agency of parents and especially mothers, while they are still alive, is often ignored, despite its importance in mitigating both current and *future* child vulnerability. Research needs to focus on such questions as parents' roles while still alive in ensuring the future livelihoods and well-being of their children. How can programmes work toward ensuring that children experience familial connections once their parents have passed away? How can parents become involved with saving for their children's future and bolstering the capacity of future caregivers?

- *Improve the quantity and quality of monitoring and evaluation systems*

The findings from the meta-analysis of Rivers *et al.* (2004) have several policy implications in terms of how to conduct future monitoring and surveillance of children made vulnerable by HIV and AIDS. First, child weight-for-age does not appear to be the most appropriate variable to monitor changes in the nutritional and food security status of orphans. Instead, the analysis indicated that food security indicators might be more appropriate, and further research is needed on the use of food security indicators to capture differences. Second, it may be necessary to use indicators, such as psychosocial development or educational attainment, to monitor the progress or relative disadvantage of orphans.

The number of programmes to assist OVC, their households and communities have been growing at a steady pace, but only a handful of them have been evaluated. This is partly because understanding of the complexities of household coping responses, local caregiving practices and stigma is still lacking, as are data on school enrolment rates, the number of children caring for sick family members and the number of child-headed households (Deininger *et al.,* 2003) Second, since many interventions are still in their infancy, it may be too early to evaluate them meaningfully.

Conclusions

This review has attempted to shine light on the particular vulnerability of children in the context of what HIV and AIDS is doing to families and communities in sub-Saharan Africa. Accordingly, some aspects of the vulnerability have been clarified, while others remain a little blurred. In some cases, the context-specificity of interactions and impacts generates what may be referred to as "contradictory results", which are not immediately policy-friendly. This is hardly surprising when considering the myriad factors and processes that determine the nature and degree of the multiple impacts that occur. Impacts and responses are determined by the dynamics in several contexts (demographic, epidemiological, socio-economic, cultural, psychosocial, organizational), as are the impacts and responses to other stressors beyond HIV and AIDS.

We must thus caution against over-generalization in interpreting any particular study's findings. The number of studies is still limited, and further research is needed to improve our power to predict consequences and needs in distinct contexts. Such a diversity of impacts needs to be matched by diversity among researchers working collaboratively. Bridges need to be built between social scientists, epidemiologists, public health specialists, nutritionists, agricultural economists and other professionals.

Although more and better research is clearly needed, there is also an immediate need for concerted and large-scale action. A useful approach for most stakeholders is thus to adopt a structured "learning-by-doing" mode and progressively build a library of operationally-relevant research from various contexts while developing tools and processes to turn evolving local understanding into appropriate local responses.

Strategically, the principle of capacity strengthening from the ground-up, viewed through the eyes of a vulnerable child, is central. The aim is to build on what is working, including extended family support, and augment such local responses through strengthening community capacity and progressively aligning sectoral support and incentives.

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ANNEX: EXAMPLES OF COMMUNITY RESPONSES AND INNOVATIONS

Kenya

The *National Children in Need Network* (NCNN) was formed by 56 Kenyan-based organizations under the *African Network of Prevention and Protection of Child Abuse and Neglect* (ANPPCAN). NCNN is a national NGO that allows the member organizations to coordinate their programmes aimed at improving living conditions of children in difficult circumstances, such as those orphaned by HIV/AIDS. NCNN works in Kenya on a national level to implement the *Convention of the Rights of the Child*. NCNN was created under the *Child Rights Information Network* (CRIN), which receives funding from Save the Children (Sweden), Save the Children (UK), Plan International, and the International Save the Children Alliance (Ayuku *et al.,* 2004 and CRIN 2005).

Mozambique

The approach of Mozambique's *Hope for African Children Initiative* (HACI OVC) is to expand on already established HIV/AIDS, livelihood and microfinance programmes. A strong emphasis is placed on training individuals who work with children in the communities, such as social welfare service providers and traditional leaders. In sum, this project aims at "scaling up" all existing interventions – increasing the capacity to care for OVC; increasing OVC awareness and advocacy activity; and increasing the number of organizations on all levels that respond to OVC needs. HACI OVC was established in 2000 by CARE, Plan, Save the Children, the Society for Women and AIDS in Africa, the World Conference on Religion and Peace, and World Vision (CARE 6/2003 and HACI, 2004).

Namibia

The *National OVC Program of the Government of Namibia* consists of three projects. *Schooled for Success* aims to ensure that OVC not only attend, but also succeed in school through a major campaign for the right to education for OVC, community-level psychosocial support, and the provision of school uniforms and supplies. *Psychosocial Training for OVC* trains peer counsellors and identifies youth leaders to provide care and support. Peer counselling and coping is taught through experiential learning camps. The *AIDS Law Unit of the Legal Assistance Centre* focuses on the rights of PLWHA and OVC. This project has drafted the National OVC Policy and the National HIV Policy for the Education Sector, which targets OVC rights. The Namibia OVC Programme has also developed a national monitoring and evaluation system in addition to an OVC identification programme and database. The National OVC Programme receives support from NGOs and donor agencies including USAID/FHI (FHI, 2004).

South Africa

The *Pietermaritzburg Child and Welfare Society* (PCW) is a partner organization of the *Children in Distress Network* (CINDI) in South Africa. It identifies and trains foster parents and places them with orphans with special needs. The training programme consists of home-based care, case management, bereavement and support services. PCW also keeps a home that serves as a short-term safe shelter for orphans and an adoption programme (Strebel, 2004). A member of the CINDI in South Africa, the *AIDS Orphan Project* (AOP) identifies and registers OVC by means of childcare committees. The project also assists in identifying appropriate foster families for OVC and ways to provide support to those families caring for OVC. AOP collaborates with other organizations to provide community training and teach income-generating skills. CINDI operates with funding from the Rockefeller Brothers Fund and Development Cooperation Ireland (CINDI, 2005 and Strebel, 2004).

Siyawela, a community-based programme in South Africa, collaborating with USAID, Family Health International, the Perinatal HIV Research Unit of Chris Hani Baragwanath Hospital and community health clinics, tracks and supports OVC. The programme consists of community mobilization, community childcare, a referral system and tracking. The delivery of services such as counselling, life skills training, home-based care and nutritional support provide holistic care to meet the needs of OVC. In 2001, approximately 3,500 OVC were reached through counselling and support groups. Determining community strengths, weaknesses, resource availability and OVC needs through focus group discussions allows for sustainable interventions (HOPE Worldwide, 2004).

Southern Africa

The *Southern Africa AIDS Training Programme*, funded by the Canadian International Development Agency, supports local organizations in Zimbabwe and other countries to provide the following: orphan visits, assistance in forming anti-AIDS clubs in schools, and support for keeping families well-nourished, educated and counselled (CIDA, 2004).

Swaziland

As a response to the declaration by King Mswati III that the HIV/AIDS situation was a national disaster in 1999, Swaziland recognized the need for short- and long-term orphan care interventions. In a collaborative effort, several organizations (WHO, CARITAS-Switzerland, and local businesses) helped Swaziland develop a community-based approach. This coordinated assistance process to OVC ensuring food security, access to resources, and shelter to these children. To make the programme truly community-based, village leaders were identified in order to raise their awareness on their invaluable role in the projects. Organizations, both international and local, contributed food, manpower, fuel, generators, transportation and tools for building a two- room house to replace dilapidated huts of one family of orphans left behind by their parents. CARITAS used spare building material to construct a pit latrine for the orphans and led the children in planting and maintaining a vegetable garden (WHO/AFRO).

Tanzania

Through the collaboration of NGOs, religious organizations, international agencies, and the government, *Godfrey's Children* promotes community empowerment in Tanzania. This programme offers a vast range of projects including: all levels of education (primary, secondary, post-secondary and vocational); monitoring of research findings on the care of OVC and children infected with HIV; and tailored HIV awareness such as educating pre- and post-natal HIV positive mothers on safe breast-feeding practices. Godfrey's Children is a project under the International Federation of Medical Students Association, with further collaboration with the Save Africa from AIDS (SAFA) Campaign, Africa Bridge, People to People, and the Foundation for Sustainable Development (Godfrey's Children 2002).

HUYAWA (Service for Children) is a program concerned with the well-being of orphans, working with five major programs: education, healthcare, legal rights, social care and seminars. HUYAWA provides educational support for orphans by enrolling school-age orphans, paying school fees, providing school uniforms and other materials. For post-primary schools, HUYAWA covers travel and tuition costs. From 1989–1999, HUYAWA provided assistance to 274,557 orphans. HUYAWA receives support from the Swedish International Cooperation Agency (SIDA), the Church of Sweden Mission, and the Tanganyika Christian Refugee Service (Mushi *et al.,* 2002).

Uganda

Through *Uganda Women's Effort to Save Orphans* (UWESO), mothers widowed by HIV/AIDS learn finance and work skills to become self-reliant. Some children orphaned by HIV/AIDS are adopted while others are supported through the collective efforts of their communities. Still others (approximately 2,000 per year) receive educational sponsorship. Those children who are not adopted reside in the Masuliita Children's Village, which provides them with a nurturing environment in which to thrive. Children are also trained in marketable skills through the Artisan Skills Development Program to earn a living in their communities. Emotional counselling and nutritional support are also offered as valuable services with UWESO. Through support by donors such as USAID and UNICEF, the programme has reached 22,209 households, where over 100,000 orphans reside (Kiarostami, 2001; Ntambirweki, 2005; UWESO, 2002).

The *AIDS Orphan Education Trust* (AOET) in Uganda is an "independent, indigenous, non-governmental organization" that assists OVC in several ways, including through orphan education and family placement homes; computer training for older orphans; HIV/AIDS awareness programmes in remote regions; and a mobile clinic that provides medications for common opportunistic infections, home-based care, and counselling services. AOET has founded a school for 100 orphans up until today. AOET finds orphan placement services valuable as research has shown the importance of the family, rather than an institution, in the ability of OVC to maintain balanced lives. The computer training centre is also vital to the success of AOET's interventions because it provides self-sufficiency to programme participants. With the mobile clinic, AOET covers a significant area, visiting 63 villages in three counties in Uganda. AOET provides services through fundraising, donations and partnerships with Assist International and Children of Grace (AOET).

Zambia

In Zambia, the government, NGOs and UNICEF have collaborated to establish the Children in Need Network (CHIN). CHIN aims at providing support to registered NGOs and CBOs working with vulnerable children (*www.chin.org.zm*). While the organization does not directly provide food aid or nutritional support, it works to promote and foster economic empowerment for households through programmes, training and income-generating activities so that families who have taken in orphans are better equipped to handle the increased economic burden. Partners of CHIN include UNICEF, Save the Children (Sweden), the World Population Foundation and Street Kids International.

The *Strengthening Community Partnerships for the Empowerment of Orphans and Vulnerable Children* (SCOPE OVC) programme catalyzes partnerships between government, local volunteer groups, private sector organizations and churches to provide assistance to those caring for children orphaned by HIV/AIDS in 12 districts of Zambia. Assistance is tailored to the specific needs of a particular community, including feeding and educating OVC, developing HIV/AIDS prevention strategies, and introducing income-generating projects to create economic opportunities. The main objective of SCOPE is to create a multi-sectoral approach to OVC care by incorporating community consultation, involvement and commitment, as well as initiatives for the improvement of household economic security. In 2001, approximately 90,000 OVC received assistance, one-third of whom received support in the form of education. Among SCOPE's many significant accomplishments is the development of several training manuals, guides, and newsletters. The project was developed by CARE-Zambia and Family Health Trust (Hemes, 2003; Strebel, 2004).

Zimbabwe

Zimbabwe's *Community-Based Orphan Care Programme*, initiated by the Department of Social Welfare and UNICEF, aims to maximize community involvement in caring for OVC. The two districts of Masvingo and Mwenezi have adopted the phrase "*nherera ndedsedu*," which means "orphans are ours." The village committee is responsible for daily activities such as registering and keeping records of all orphans in the village, providing services to OVC and their caregivers, and mobilizing funds for the welfare of OVC. School fees for the orphans are paid for by village contributions and child welfare funds. Community income-generating projects have also been employed, such as goat rearing, building grinding mills, and coffin production (Matshalaga, 2000).

Zimbabwe's *Family AIDS Caring Trust* (FACT) consists of two programmes. The *Families, Orphans and Children Under Stress* (FOCUS) programme recruits volunteers from local churches who are trained to visit orphans in their homes to assess their needs and distribute small-scale assistance with food and seeds. After evaluation in 1999, FOCUS had provided care for nearly 9,000 orphans, 1,000 of whom received school fees. FACT provides the training, support, school fee funding and programme management. *Farm Orphan Support Trust* (FOST) aims to keep sibling orphans in a familiar environment by using farm development committees that train orphan caregivers, provide orphan registration and household visitations, and raise awareness among farm owners. Channels that function in monitoring care on farms are also established. Initial funding for FACT was awarded by Plan International (Mutare). FOCUS began with a start-up grant provided by Save the Children (US). Since 1993, supplemental funding has come from USAID (NAM 2005; Strebel, 2004).

Zimbabwe's *Support to Replicate Innovative Community/Village Level Efforts for Children Affected by HIV/AIDS* (STRIVE) began as a pilot programme through a grant awarded to Catholic Relief Services by USAID. The programme supports OVC and their communities by providing grants to 16 organizations on both the local and international levels. These organizations develop projects that aim to improve education, food security, and psychosocial development. STRIVE has reached nearly 54,000 OVC in a four-year period. An example of an organization that STRIVE funds is *Batsiranai*. Through Batsiranai, HIV/AIDS awareness is accomplished by using components of community theater, such as drumming, traditional dance and song. Awareness of children's rights is increased by allowing OVC to participate in advocacy by sharing stories about their experiences of exploitation, such as child labour, since losing their parents to HIV/AIDS (CRS, 2004).

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