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Acronyms

AZT	Drug used to treat HIV
HBC	Home based care
HIV	Human immuno-virus
IEC	Information, education and communication
MTCT	Maternal to child transmission
PLA	Participatory Learning Activity
OVC	Orphans and vulnerable children
SRA	Structured Recreational Activities
VCT	Voluntary counseling and treatment

Executive Summary

AIDS-affected children include orphans and children whose parents are ill or too busy caring for ill family members. Very little is known specifically about the 0-4 AIDS-affected age group, since most orphan assessments treat the 0-15 (or 0-18) year age span only as a whole. Because of their nutritional, health and psycho-social needs, children under age 5 represent a group that demands special attention.

This paper presents 1) current knowledge about the caring situation of AIDS-affected children under 5 years of age, 2) pre-existing tools relevant for assessing young child care, and 3) new assessment tools specifically targeted to assessing the care of AIDS-affected children under 5.

Extrapolations from sero-prevalence statistics among pregnant women, general orphan assessment, literature on common beliefs about AIDS and orphans, and pre-epidemic studies of child-rearing in sub-Saharan African reveal a grim picture for children under 5. Results suggest that high proportions of AIDS-affected infants and young children will either die young (even if not infected with HIV) or survive under conditions that will permanently diminish their nutritional status, their health, and their ability to function in society as adults due to poor psycho-social care in early childhood.

AIDS-affected children under 5 are at special risk from mother-to-child transmission of AIDS and from malnutrition due to lack of breastfeeding, the difficulty of providing alternative foods, and young or elderly caregivers' ignorance of alternative foods. They are at special risk from both common and immunizable diseases because young and elderly caregivers lack the knowledge, time, funds, or commitment to seek health care. They are at special risk from poor psychosocial care because they are less likely to have consistent caregivers with the time and commitment to offer it.

In addition, AIDS-affected children under 5 are further endangered by specific beliefs related to AIDS, feeding, immunization, orphan status, and the treatment of household assets after a death. The extreme difficulty and multiple fears that surround the care of AIDS-affected young children simultaneously inspire admiration for caregivers undertaking this task and deep concern about the mental, emotional, and physical survival of this age group.

Functioning programs primarily directed to the under-5 group seem to be few and far between. Only 11 such programs in 4 countries were identified; costs of orphanages and transit houses were high and capacity was low—often less than 200 children each. While many other programs must exist which address their needs directly, and many programs exist which indirectly affect their needs, these numbers are distressing.

Pre-existing tools, from four major studies and 10 others for which less information was available, for assessing orphan care are reviewed. Questions addressed specifically to the care of children under 5 are largely missing from the tools reviewed, except for research conducted by NFNC/LINKAGES/SARA on infant feeding alternatives among HIV-affected mothers.

New tools presented are designed for use in participatory community assessments in four areas: feeding, health, caregiver consistency, and stimulation. Program design options for each category are offered. Child care receives special attention in both

assessment and program options. Child care services can deliver food, health, and psychosocial support directly to children under 5. Child care can play an important role in providing respite to elderly or sick caregivers, opportunity for income-generating activities for adults and older children, opportunity to attend school for school-aged children, and support for community volunteers working on AIDS related issues.

Adult deaths from AIDS are already draining Africa's work force of power and talent. The financial and labor demands of households devastated by AIDS are forcing the next nearest generation out of school. If the youngest generation of all is wasted physically and mentally in the surrounding pressures, then it is truly difficult to see how countries themselves will survive. Attention to the needs of children under five and their caregivers can provide a pivot, turning these trends around. Better use of food and health services can liberate already grieving households from the grief of sick and dying children. Better use of time resources can free adults to work and farm; it can free older children to attend school. And it will preserve a generation of survivors much better able to meet the challenges of the post-epidemic years.

Introduction

This document examines the state of knowledge and art regarding young children affected by AIDS.

AIDS has orphaned more than 11 million children in the developing world. This number is expected to increase dramatically in the next decade. Each year another 1.6 million children become orphans (UNICEF/UNAIDS, 1999). UNICEF estimates that 1 in 3 of these children is young – 5 years old or younger.

The number of young children *affected* by AIDS is much greater. Young children affected by AIDS include those whose parents are already very ill and will die in the next few years; children whose caregivers are overwhelmed by the tasks of caring for sick relatives or replacing their lost income and labor; and children whose households are overwhelmed by the orphans of relatives.

Many nutritional, health and psycho-social challenges threaten AIDS-affected children under age 5, the majority of whom live in Africa. Research, agency reports, and news articles about AIDS orphans and vulnerable children generally treat the whole 0-15 year age span as an integral group. There is little emphasis on the special problems and risks of very young children affected by AIDS and how to ameliorate them. School attendance is sometimes highlighted for school-aged children; young adolescents are focal points for prevention research and programming. “Orphan care” in an article or report title often refers to reports on the housing of orphans, other aspects of care being assumed in that identification alone. Children under two receive attention in mother-to-child transmission reports, but for the most part the mortality statistics, not how children are cared for, have center stage. The incidence of orphans absorbs the most concern.

Considering the numbers of children and the dimensions of the problems they face, we undertook a review of the current situation of AIDS-affected children under 5—and uncovered a great gap in information. We discovered no tools designed for assessing the care of AIDS-affected children under 5 and very few studies and programs directed to this age group. In order to present an evidence based picture of the situation, it was necessary to triangulate from studies of older orphans, beliefs about AIDS and orphans, pre-epidemic child-rearing practices, and assessments of AIDS-affected communities.

This paper attempts to fill the information void about young children affected by AIDS through reviewing:

- 1) Numbers and distribution of young children affected by AIDS
- 2) Special problems facing AIDS-affected children under age 5 and their families, households, and communities
- 3) Beliefs and traditions that affect care of young children
- 4) Tools that can be used for assessing their care and
- 5) Strategies for developing program activities to improve their care and development.

The challenges that AIDS presents to infants, toddlers and preschool children are not unique; they also can be caused by other stresses within a community or family. Programs need to address all children in exceptionally difficult circumstances within a community, and not just those directly affected by AIDS. Children affected by AIDS should not be singled out as a special group, since this can further isolate and stigmatize

them in their communities. children affected by AIDS are arguably the group at most at risk of inadequate care and neglect, with serious negative consequences in their lives and their societies. As the next section shows, there are growing numbers of these children, and potentially, growing long term problems for their societies.¹

- 1) parent-headed households where parents are sick and dying,
- 2) elder-headed households where the grandparent is incapacitated,
- 3) households where caregivers are overwhelmed with caring for AIDS adults or by the demands of fostering their relatives' orphans (Foster et. al., 2000).

Other categories of vulnerable children less directly affected by AIDS can also be included in this term. In countries with severe HIV epidemics, no family has escaped the impact of AIDS; as a result, the situation of other vulnerable children such as the disabled, the destitute, and child laborers is affected—worsened—by AIDS.

Age distribution and number of orphans and AIDS-affected children

The number of vulnerable children affected by AIDS is difficult to quantify. Demographic estimates have been used to estimate the number of AIDS-affected orphans. In Zambia, 13% on average, ranging from 11% -18% of all children in different provinces, have lost at least one parent, and in Kenya 12% of children have lost a parent.

Several studies have estimated the number of orphans in Africa, however, only a few studies have illustrated the proportion of orphans who are under age 5. In Zambia, the proportion of orphans less than age 5 is estimated at 10% and In Uganda 15%.

Table 1 summarizes these findings and suggests that from 10% to 15% of AIDS orphans are under the age of 5 years, and UNICEF estimates that 1 in 3 are orphans. **Based on the DHS results, which are nationally representative, it appears that the UNICEF**

¹ Notes on Terminology for Children Affected by AIDS

Orphans: The term “orphans” in most studies refers to children under 15 who have lost one or both parents. (In rare cases all children under 18 years of age or only children whose mother has died are counted as orphans. The under-15, either-parent criteria are used in the majority of reports.)

Other vulnerable children: Orphans and other vulnerable children (OVCs), are being grouped more and more often as agencies realize that isolating “orphans” as a group contributes to their social stigmatization and often makes little sense to community groups. “Orphan”, moreover, is not a term normally applied in Africa to any child who has any relatives who can provide care; often orphans and neighbors struggle with the same food, health, education, and economic difficulties. (Tembo, Kakungu, and Manda, 1999).

Children Affected by AIDS: This review will use “Children Affected by AIDS” to draw attention to circle of extreme difficulty immediately surrounding children in the AIDS epidemic. It will refer primarily to children who are living in households with limited caregiving available:

- 1) child-headed households,
- 2) parent-headed households where parents are sick and dying,
- 3) elder-headed households where the grandparent is incapacitated,
- 4) households where caregivers are overwhelmed with caring for AIDS adults or by the demands of fostering their relatives' orphans (Foster et. al., 2000).

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figures are closer to reality . Using the UNICEF estimate, and assuming that for each orphan, there is at least one additional child severely affected by AIDS, then we estimate that **there are nearly 7 million vulnerable children under age 5 affected by AIDS.**²

Table 1. Number of Orphans and proportion under age 5 in selected African countries						
Country	Year	% of children who are orphans Mean (range)	No. of orphans	No. of orphans < 5	% of all orphans who are < 5	Date source (Reference)
Zambia	1996	13% (11-18%)	550,000 (< 18 yrs)	55,000	10%	Living Conditions Monitoring Survey (1996)
	1996	13% (3% of children – 0-2 yrs; 8.2% of 3-5 yr olds; 13.6% of 6-9 yr. olds, 17% of 9-14 yr. olds)				DHS, 1996
	1990	22%	890,000 (< 15 yrs)			Estimates using fertility /mortality rates(Hunter and Williamson, 1997)
	2010	34%	1,700,000(< 15 yrs)			“
Kenya	1996	11% (3.8% 0-2 yrs; 5.3% 3-5 yrs; 10.3% 6-9 yrs; 13.7% 10-14 yrs)				
	1999	12%	1,500,000			Donahue et al, 1999 (Based on figures from U.S. Bureau of the Census)
	2010	20%	2,300,00			“

² 3.3 million orphans plus another 3.3 other vulnerable children.

Uganda	1996				15%	Konde-Lule et. al, 1996
	1995	11.6%	1,037,228			Ntozi, 1997
Tanzania	1991	10.8				Hunter et al, 1997
	1996	8.5% (2% 0-2 yrs, 5.4 3-5 yrs, 9% 6-9 yrs, 14.5% 10-14 yrs.				DHS, 1996
	2000		1,000,000			Hunter et al 1997
Zimbabwe	1994	10% (2.5% 0-2yrs; 5.7% 3-5yrs; 7.8% 6-8 yrs; 14.1% 9-14 yrs)				DHS, 1994
	2000	17%	670,000			Foster et al, 2000
	2005	33%	1,100,000			Hunter and Williamson, 1997
	2010	36%	1,500,000			Hunter and Williamson, 1997

The blank cells in the matrix illustrate the lack of information about very young orphans. Epidemiological analysis and modeling of cohort distributions, AIDS trends, birth rates, and background mortality rates could provide better population based estimates of HIV mortality. Other AIDS related excess mortality among young children, probably associated with inadequate care, could also be modeled and analyzed.

Prevalence of HIV in women of reproductive age and their children

The rates of HIV in pregnant women illustrate the ongoing and increasing problem of AIDS for children under 5 in different parts of Africa. Table 2 gives estimated rates of HIV infection among pregnant women for several countries in Africa. These rates range from 12.7% in rural Zambia to 43% in Botswana.

Although HIV is so highly prevalent, programs to provide treatment with anti-viral drugs to pregnant women to prevent transmission of HIV to their infants are currently operating only in research projects. Even with reduced cost of drugs for treatment, the costs of scaling up these programs are likely to be beyond the means of the countries where AIDS is most prevalent.

Table 2. Proportion of pregnant women who are HIV+ in selected African countries				
Country	Year	Area of country	% of pregnant women Mean or range	Date source (Reference)
Botswana	1998		43%	Achieng', 1998
Malawi	1999		Over 25%	UNICEF/UNAIDS, 1999).
Tanzania	1995	Dar es Salaam	13.7	US Census Bureau
	1995	Rural	16.6	US Census Bureau
Zambia	1998	Lusaka	27%	US Census Bureau
	1994	Rural areas	12.7%	US Census Bureau
Kenya	1998	Busia and Kisumu	>20%	Donahue et al, 1999
		Kakamega and Kisii, the North and Southeast of Nairobi and in Mombasa	10-20%	Donahue et al, 1999
Zimbabwe	1997	Harare	28%	US Census Bureau
	1997	Makoni (rural)	29.3	U.S. Census Bureau

Care for children under 5 affected by AIDS

Little is known about the care of children under 5 affected by AIDS, although there is every reason to believe that they are the most vulnerable of this extremely vulnerable age group. AIDS-affected children under 5 present enormous challenges to their caregivers. Their care is more time-consuming and labor-intensive than care for older children. They are more vulnerable to potentially fatal malnutrition, diarrhea, and

pneumonia, and thus are more costly to care for and less likely to survive than older children affected by AIDS (NAS COP, 1998); they represent a greater risk of lost effort, investment, and heartbreak.

As orphans, children under 5 are the least welcome foster children. They can contribute almost nothing to household work or income and require the most intensive care. Having been born closer to a parent's death in time than older orphans, young children are more likely to be seen as *part* of the death, bringing with them contagion or the curse of witchcraft. In some societies, it is very difficult for caregivers to make the intensive investment of time, energy, emotion, and money in the care of young children they see as both dangerous and likely to die.

Consequences of inadequate care for young children affected by AIDS

Young children affected by AIDS who do not receive good care are likely to be impaired in multiple ways if they survive. The absence of adequate nutrition, health care, and psycho-social interaction will permanently damage children's ability to think, learn, and function effectively. Malnutrition that occurs during the first few years causes irreversible stunting and impaired cognitive functioning well into late childhood (Mendez and Adair, 1999). Damage done to young children who are deprived of consistent caregivers and simple interpersonal and environmental stimulation has long-term cognitive and psychosocial consequences. The horribly stunted development of children emerging from Romanian orphanages has provided the world a vivid picture of the effects of extreme neglect.

Studies show higher levels of physical, cognitive and emotional well-being and better rates of lifetime learning and earning with good early childhood care. By contrast, people without quality care in the early years are more likely to fail out of school, turn to a life of crime, and perpetuate the cycle of poverty as adults (Deutsch, 1999). Neglect of young children therefore has longterm, significant negative impacts on a society.

Special problems facing vulnerable children under 5

Vulnerable children under age 5 in AIDS-affected areas face special risks related to their survival, feeding, health, and psychosocial care.

- Approximately one third of children born to sero-positive mothers will be infected with HIV, and
- All children, whether or not they are infected with HIV, who are born to AIDS-affected families, are at heightened risk of
 - mortality,
 - morbidity, and
 - psycho-social damage

Survival: Risk of AIDS infection

About 20 percent of infants of HIV-infected mothers are infected before or during delivery. If all HIV-infected mothers breastfeed, an additional 14 percent of their infants would be infected through breastfeeding (LINKAGES, 1998). These estimates, based on average transmission rates in several studies, closely correspond to the reported rates of transmission. For example, in Kenya, 30-40% of babies born to HIV+ mothers are infected (NASCOP, 1998) and 27% of infants are reported to be infected in Uganda.

As stated by Panos, 1997, "AIDS kills children far faster in developing countries than in the West." In Europe, eighty percent of HIV-infected children survive at least until their third birthdays, and more than 20% reach the age of ten. In Zambia, however nearly half of the HIV-infected children in one study were dead by the age of two. In another study in Uganda, 66% were dead by the age of three (ref?). Massawe and Taylor, 1999 report that 50-75% of children in developing countries infected with the virus die before their fifth birthday.

The impact on projected under-five mortality is devastating:³:

- Kenya: Under-5 child mortality is projected to skyrocket from 45 per 1,000 live births to 105 by 2010 (USAID and USDOC, 1999).
- Malawi: The under-5 mortality rate is expected to increase from 190 to 232 per 1000 live births by 2010 (USAID and USDOC, 1999).
- Namibia: By the year 2005 AIDS will be responsible for 48 percent of deaths of children under age five in Namibia (IRIN, 1999).
- South Africa: By the year 2005, AIDS will be responsible for 50% of deaths of children under five, (UNICEF, 1999).

³ For example, under-five mortality (CMR) is defined as the number of deaths to children under 5 years of age per population of children under five (or the probability of dying from birth to exact age 5). In Kenya, the CMR was estimated by the Department of Commerce at 45 deaths/1000 (although DHS estimates suggest higher rates). If the proportion of pregnant women who are HIV + is 25%, if 34% (20% via pregnancy and delivery and 14% via breastfeeding) transmit HIV to their infants, and if all children born with HIV die by age 5, then 8% (25%*34%=8%) of children will die of AIDS by age 5. In other words, out of 1000 live births, 80 will die from HIV. If the base rate is 45 (assuming minimal impact of HIV) then the future rate of child mortality (assuming all children with HIV would not have died of other causes) would be 80+45/1000=125. Assuming some of the HIV-infected children would have died from other causes, reduces the projected rate to 105.

- Zimbabwe: The mortality rate among children under the age of five will be three and a half times higher than it would be without HIV/AIDS by 2010. (UNICEF, 1999).

Families and health services may be overwhelmed trying to care for and treat such children. Triage at tertiary care facilities is already widely reported. Differential treatment at primary care facilities may also be prevalent.

The 2/3 of children born to HIV positive mothers who are not infected and survive may be drastically affected by the “message” caregivers take from these high mortality rates. Families coping with the costs of sick and dying adults and children have few economic and emotional resources to spend on surviving children. Most critically, they may be so discouraged by the low survival rate of young children in epidemic times that they fail to spend life-preserving and life-enhancing resources of time and care on the very young.

Abandonment of infants

Abandonment of young children is particularly devastating because they are unable to fend for themselves. Many HIV-positive women were reported in Kenya to abandon their newborns in the hospital where they delivered (even though such infants may not be HIV+); in the public hospitals, where resources for these abandoned babies are limited, the majority die within a few months. (Petito, 1996).

In Lesotho, as widely reported anecdotally infants who are believed to be HIV positive are being abandoned by their mothers in hospitals and children’s homes. In addition, children who are HIV+ have been neglected by facility staff because it is believed they will die (Hunter and Kalaka, 1999).

Nutrition

Prior to the impact of the AIDS epidemic, African children suffered high rates of malnutrition as Table 3 below shows below for Kenya in 1993.

Table 3. Nutritional Status of children in Kenya 1993 (% of children under 5 who are classified as undernourished)							
Age in months	Low Height-for-age		Low Weight-for-height		Low Weight-for-age		Number of children
	Percentage below -3 SD	Percentage below -2 SD ¹	Percentage below -3 SD	Percentage below -2 SD ¹	Percentage below -3 SD	Percentage below -2 SD ¹	
Under 6 mo.	1.2	7.5	0.2	4.3	0.6	3.5	411
6-11	4.3	18.1	1.1	4.8	4.2	16.1	537
12-23	14.3	40.3	2.3	10.0	8.5	31.6	988

**Table 3. Nutritional Status of children in Kenya 1993
(% of children under 5 who are classified as undernourished)**

24-35	15.1	37.7	0.7	5.4	7.1	26.2	945
36-47	14.9	37.3	1.4	4.7	5.4	22.0	1000
48-59	13.5	34.5	0.7	4.7	4.5	20.4	872
Total	12.2	32.7	1.2	5.9	5.7	22.3	4752

¹ Includes children who are below -3 SD

Source: Macro, International, 1993.

Most studies report that orphans under 5 are more likely to be stunted or malnourished than non-orphans (Tembo and Kakungu (1999), Semali et al, 1995; Poulter, 1997; Nduati et al, 1993), but Foster (1993) reported no difference. No studies controlled for bias due to increased likelihood of HIV infection in orphans or for increased mortality of such children. The rates of malnutrition in Africa, however, may be worsening in AIDS-affected communities as AIDS becomes more prevalent and household agricultural and livestock production is reduced, as children become ill, and families are overstressed.

Children ages 6-36 months of age: Breastfeeding

Maternal orphans, children of mothers who are too sick to breastfeed or mothers who know they are HIV positive and choose to not breastfeed, are deprived of essential nutrition in breastmilk, protection against common diseases, and the guaranteed physical and psychosocial interaction that accompany breastfeeding.

Normally, 97% or more of infants born in Kenya, Tanzania, Uganda, Zambia and Zimbabwe are breastfed, for median durations of 19-22 months. Such high rates of breastfeeding help protect infants and toddlers from malnutrition and illness. Breastfeeding provides optimum energy, protein and micronutrients for young infants and toddlers. Because of its anti-infective properties, breastfeeding helps prevent or reduce the severity of common illnesses, especially the diarrhea and pneumonia that are major causes of death in developing countries.

Despite the need for special milk or formula to replace breastmilk when a mother is dead or acutely ill with AIDS, the high costs of such foods make it difficult for families to provide in sufficient amounts for infant feeding. In addition, ensuring such milks are fed under hygienic conditions is extremely difficult in poor environments. The fuel, utensils, water and soap needed for hygienic preparation add cash, time, and energy costs may well be beyond the means of over-stretched caregivers. Caregivers in child-headed households or elder-headed households of AIDS-affected children often lack knowledge, as well as funds and time, to provide adequate replacement feeding.

Children ages 6-36 months of age: Complementary feeding

All children over 6 months of age need appropriate complementary feeding along with breastmilk to meet the child's nutritional requirements. Many children in Africa, however, even those unaffected by AIDS are malnourished, because of the difficulties families

have in appropriately feeding their children. For example, as shown in Table 3, rates of stunting jump from 8% in children under six months of age, to 18% for those 6-11 months to 40% for those 12-23 months.

Most infants and toddlers are breastfed. In some communities there is inadequate understanding that AIDS-affected children over six months of age who are not breastfed need special and additional foods beyond milk substitutes. Child- and elder-headed households in particular may lack knowledge of appropriate foods, or because of time and financial constraints, shift too quickly to adult foods.

Children ages 3-4: Family foods

Children ages 3-4 should be supervised during meals, and given snacks during the day in order to meet their energy requirements. High rates of anemia and other nutrient deficiencies such as vitamin A and zinc have been observed among many children under age 5, and few affordable foods contain sufficient iron and zinc (meat is a particularly good source) to meet their needs. Increasing access to fortified foods and supplements (such as high dose vitamin A) can help address these concerns. Caregivers in AIDS-affected households may lack knowledge, time and resources to procure and prepare energy dense, micronutrient rich foods; to offer food at sufficiently frequent intervals for small stomachs; to monitor eating; and to actively and responsively feed young children.

Food discrimination

Orphans in focus groups have reported that the very little that there is in the household is often not shared with them (Ayieko,1998) One orphan reported: "When my relatives cooked food they used to hide it from us". Another orphan told how he was sent to collect firewood and in his absence the bit of food there was given out to the non-orphan children. A Kabwe male orphan summarized the situation in the following words: " We (orphans) do not mind not having enough food or clothing. After all everybody else is in this situation because of poverty. What we mind is being regarded different by the rest of the family".

Piwoz reports the special difficulties faced by the under-5 age group. "Nutritionally, the under-5s are very, very vulnerable...families can't afford to feed them...Everyone is assuming that the younger kids are being taken care of...This is Africa and Africans take care of kids," but "Little kids fall through the cracks" (NFNCLINKAGES/SARA, 2000).

Even in the best of circumstances children under 5 can be fussy, disorganized, slow and erratic eaters, easily thrown off track by colds, distractions, and minor discomforts. Giving young children time and attention around eating when time is scarce and food scarcer presents tremendous challenges to caregivers.

Health concerns

As Foster (1998) points out, children under 5 who are maternal orphans are extremely vulnerable to serious illness "since elderly and juvenile caregivers are frequently uninformed about nutrition, oral rehydration, immunization, and diagnosing serious illness." These same issues may apply to all AIDS-affected children under 5, as

overwhelmed adult caregivers transfer many care concerns to older children and grandparents while they attend to ill adults or other multiple issues arising from care for large numbers of foster children. Kamenga et al (1990) found higher rates of missing scheduled clinic visits among infants born to HIV+ mothers due to “premature maternal death from HIV infection and lack of a suitable guardian”.

Improved survival rates in an orphan hospice in Nairobi suggest that malnutrition and lack of attention to health issues plays a significant role in under-5 orphan mortality. The hospice cares for children born to HIV+ mothers, ordinarily a high-mortality group in Kenya. The feeding and prompt treatment for opportunistic infections offered at the hospice makes a difference: 56 out of 60 children admitted in the first year and half remained alive and well (Mwangi, 1994).

Common infections

Diarrhea and acute respiratory infections are the major causes of death for young children in developing countries. Maternal orphans and children whose mothers are too sick to breastfeed or choose not to because of HIV concerns will be at much greater risk of contracting these illnesses.

A recent meta-analysis was conducted to assess the risk of mortality among non-breastfed compared to breastfed infants in developing countries. This study illustrated that when all deaths occurring after the first week were included, the pooled odds ratios (and 95% CI) of risk of dying from diarrhea and acute respiratory infections were 4-6 times as high for infants ages 0-3 months) who were not breastfed compared to those receiving any breastmilk. The benefits of breastfeeding remained throughout the first year of life ⁴⁻⁵.

Severity of diarrhea has been shown to be less among breastfed children even into the 3rd year of life. Non-breastfed children affected by AIDS may be at extra risk of death in each episode because caregivers who believe that these illnesses are the first signs of AIDS may be even less likely to seek treatment.

Immunizable diseases

When caretakers believe that common coughs, fevers, and diarrhea are symptoms are early signs of AIDS, when service providers are reluctant to immunize a sick child, direct and opportunity costs lead caregivers and service providers to ask themselves: why invest in a dying child? These realities and anecdotal evidence suggest that many orphans are not receiving full immunizations

When young children are stigmatized because they have lost a parent to illness and thus are considered at risk of having AIDS, some health services are unwilling to vaccinate

⁴ Age specific odds ratios were pooled odds ratios: 5.8 [95% CI 3.4-9.8] for infants <2 months of age, 4.1 [2.7-6.4] for 2-3-month-olds, 2.6 [1.6-3.9] for 4-5-month-olds, 1.8 [1.2-2.8] for 6-8-month-olds, and 1.4[0.8-2.6] for 9-11-month-olds).

⁵ In the first 6 months of life, protection against diarrhea was substantially greater (odds ratio 6.1 [4.1-9.0]) than against deaths due to acute respiratory infections (2.4 [1.6-3.5]). However, for infants aged 6-11 months, similar levels of protection were observed (1.9 [1.2-3.1] and 2.5 [1.4-4.6], respectively). For second-year deaths, the pooled odds ratios ranged between 1.6 and 2.1.

them. Also in AIDS-affected areas, the demands placed on health services may mean that fewer resources are available to provide the needed immunizations.

Attending to common illnesses and immunizations requires knowledge, time, and commitment any one of which may be lacking in AIDS-affected households. Caregivers who are very young, very old, or completely consumed with the tasks of caring for the sick or for the orphans of their relatives may simply be unable to provide basic health monitoring or services.

Psychosocial concerns

Psychosocial issues for children over 5 involve grief over the loss of parents and separation from siblings, stigmatization and isolation, and issues of physical, mental, and sexual abuse in foster households. A situation analysis conducted in Zambia (Participatory Assessment Group, 1999) reported that current care issues identified by orphan focus groups as significant problems were lack of love, outright discrimination, and the feeling of being excluded. In problem-ranking exercises, lack of love/discrimination scored more heavily than either lack of clothing or shelter. In a study by Bochow (1999) in Tanzania, older orphans expressed the need for someone who could be trusted and relied upon and understand them after the loss of their parents.

Children under 5 have even more urgent needs for love and trust from consistent caregivers, and are less able than older children to manage or satisfy those needs in other ways. Very young children are less helped by the kinds of counseling and group supports useful to older children. *The primary psycho-social issues for children under 5 involve consistency of caregivers, basic stimulation of all kinds, and responsive interaction.* These are challenges that can be met if they are understood and strategic action taken.

Consistency of Caregiver

A recent report on supporting orphan care in Kenya noted that, "Infants and young children...need to establish secure attachments to an adult care provider and develop a sense of trust, self-worth, and autonomy. Accomplishing these developmental tasks helps shape the child into the person he or she will become," (Donahue et. al, 1999).

Orphans of all ages are subject to leaving the home in which they grew up in order to be fostered by relatives. In Zimbabwe, 17% of orphans moved to relatives' households after the death of a parent (Foster et al, 1995). Thirty-three percent of children in child-headed households, mostly double orphans, relocated in the two years prior to a more recent study (Foster, 1998). A study of 1101 orphans in Kenya found that 48% of orphans moved upon the death of parents (Ayieko, 1998).

AIDS-affected children may be deprived of the opportunity for secure attachments. Young orphans may lose not only parents, but the older siblings and cousins who have spent the most time caring for them and were objects of attachments as well, because families often distribute orphans among several households in order to ease the burden of care. Foster et al (1997) report that children under 5 are especially likely to be fostered out while older siblings are left to live by themselves. Although understandable, these practices result in maximum disruption of attachments.

The grandmothers, widows and widowers, or older siblings who head orphans' new households have such greatly increased responsibilities that a crushing workload prevents much consistency in care. This workload may disrupt caregivers' availability to their own young children. Caregivers in Zimbabwe complain of the lack of time to attend to young children (O'Gara, personal communication). Piwoz reports that young orphans in Zambia are frequently cared for by rotating teenagers taking shifts—not a prescription for secure attachments (personal communication).

Stimulation

Maternal orphans under 2 years of age are inevitably deprived of the natural stimulation provided by breastfeeding, since wet-nursing, especially of infants born to mothers suspected of AIDS, is no longer thought safe in most regions. . For both older infants and toddlers, breastfeeding promotes normal cognitive and social development through stimulation and because it ensures that the child gets individualized attention and affection. Breastfeeding gives infants and toddlers the tactile stimulation of being held, the auditory stimulation of mothers' voices; they feel mothers' warmth, and learn some basic patterns of communication. Maternal orphans and children whose mothers are too ill to breastfeed, miss out on this critical contact, stimulation, and support for normal development: what will replace it?

Children in AIDS-affected households are at special risk for poor physical, emotional, and cognitive health. Disruption of attachments, lack of stimulation, and lack of the humanizing patterns of talk, play, and learning all represent serious dangers for their future functioning.

Children old enough to talk in Africa can have a variety of caregivers to stimulate and nurture their growth. In households not overburdened with grief and unusual workloads, caregivers have time and energy to tell young children stories, set them riddles, make them toys, sing and dance with them, show them how to do simple tasks that invigorate their mental capacities. In AIDS-affected households, this time and energy may be missing altogether.

Children's psychosocial environment affects their survival. In a study of nutritional resilience in a hostile environment, Zeitlin (1991) found greater weight gain and development among children who had more physical interaction, affection, and praise from their mothers and relatives, and those who received more verbal and environmental stimulation. More recently, Long et al, (1998) found that caring practices at the Kisangani Therapeutic Feeding Centers which included "conversing with the children" and "play and exercise" increased the speed and quality of recovery among severely malnourished orphans.

AIDS-affected children under 5 are further endangered by specific beliefs related to AIDS, food, immunization, orphans status, and the treatment of household assets after a death.

Beliefs and traditions with impacts on AIDS-affected children under 5

Beliefs about survival of children born to HIV positive mothers

A 23-country study recommends that information, education, and communications (IEC) campaigns “be used to help mothers understand that not all of their children are necessarily HIV-positive”—indicating that this “automatic” mother-to-child transmission is a very widespread belief (Hunter and Williamson, 1997). The belief that HIV+ mothers inevitably pass the infection to their children is common in southwestern Uganda: 44% of orphan caregivers interviewed doubted that a child born to an HIV-infected mother could escape infection (Mast et. al, 1996).

A worst-case set of beliefs for young orphan care were recorded by a study in rural Mossi areas of Burkina Faso. Infection of an infant was seen as inevitable and systematic, occurring in utero if the mother had AIDS. If caretakers believe that the orphans they care for must be infected, their commitment to provide adequate food and health care from nearly empty pockets is seriously challenged. Respondents in Burkina Faso believed that “no care should be taken of children born to women with AIDS” and that “such children should be abandoned and left to die” (Taverne, 1999). They may have held this belief because they assumed these children would die anyway, and any care would deplete scarce resources- or because of fear that orphans are inevitably contagious. These concerns are also reported, although far less prevalent, in Zimbabwe (O’Gara, personal communication

Beliefs about transmission of HIV via breastfeeding and options for alternative feeding

Burkina-Faso caregivers believed that the breastmilk of infected mothers automatically infects children. Wet-nursing was not seen as an option because this group also believed, correctly, that healthy women could become infected by wet-nursing infants born to infected mothers (Taverne, 1999). Changed wet-nursing practices are reported in rural Kenya as well (O’Gara, personal communication).

Similar beliefs were recorded in the Ndola district of Zambia. Researchers reported that “The risks due to breastfeeding are believed to be very high, and most men, women, and traditional birth attendants had the impression that all HIV-positive mothers pass the virus through breastmilk.” Babies who are not breastfed are “thought to be at high risk of dying”. Wet-nursing is no longer common in the area due to fear of HIV infection from infants.

The alternatives are also deemed virtually impossible: “All providers felt that it would be very difficult or impossible for women in their communities to safely offer replacement food to newborn babies. Most felt that people could not afford infant formula, and the time needed to boil water and clean utensils would be too great” (National Food and Nutrition Commission Ndola District Health Management Team, 1999).

If breastfeeding is believed too dangerous, and the alternatives believed too expensive in time and money, AIDS-affected households and infants must suffer at every feeding.

Beliefs about complementary feeding

In some African countries, feeding follows a hierarchy, with adults eating the good food first and the remains passed from the oldest to the youngest child (Evans, 1997). Once toddlers walk stably, they are often left to fend for themselves at meal time, especially once a younger child joins the family. These traditional feeding patterns have always meant that conditions of scarcity are hardest on young children. Fostered orphans may fare worse yet.

Beliefs about what food is good for young children also affect their nutrition. In Zambia it is thought that the sauce, rather than the solids, in the family meal is best for young children and families need encouragement to feed some of the most nourishing solids to young children (Piwoz, personal communication). In many cultures, food and even fluids are withdrawn from children who are ill. Active feeding when anorexia sets in is thus not practiced in these cultures or not initiated soon enough.

The prevalent complementary feeding patterns in much of Africa and Asia are particularly dangerous for the welfare of HIV-affected children. These patterns are characterized by premature (before 6 months) introduction of foods that have little nutritional value, that often are vehicles for infection, and that reduce the nutritional and disease preventive properties of breastfeeding. Beliefs and practices about foods and feeding of young children makes good nutrition for healthy children relatively rare, and even more rare for children who are ill or thought to be ill. However, recent research suggests that people with HIV have heightened nutritional needs even before they are symptomatic⁶. Early intervention with increased and improved dietary intake seems to improve quality and length of life.

Beliefs about counseling and testing for HIV

Another set of beliefs weighs in against getting tested for HIV. Women in the NFNC/LINKAGES/SARA study told researchers that if they found out they were HIV positive, they would have to decide to stop breastfeeding; if they stopped breastfeeding, everyone would know; people would think they were prostitutes, or promiscuous, or had AIDS, and shun them. The revelation would anger household elders and could lead to spousal violence. Whatever privacy might be achieved by health clinics would be wasted. Since most women thought they were vulnerable to HIV infection from their partners and that they cannot control that risk, the potential for testing positive is real and unknown. The public nature of the breastfeeding decision following positive results, and all its consequences, militates against getting tested at all (NFNC/LINKAGES/SARA 1999). Without testing, counseling, and access to alternative means of feeding to reduce transmission or provide security that breastmilk will not transfer high risk of infection, more and more children under 5 will be needlessly infected or affected by AIDS.

Beliefs about HIV transmission through witchcraft

Even when adult-to-adult transmission is not attributed strictly to promiscuity or prostitution, it is still a cause for shame. A community based survey conducted in 1989 in the Mpigi District of Uganda revealed that 70% of participants believed that AIDS

⁶ Piwoz, 2000

could be transmitted by sharing clothes, 37% by insect bites, 22% by witchcraft, and 22% by drinking contaminated water. Although only 60% believed that AIDS could be transmitted sexually, 71% regarded AIDS as shameful. These extra percentage points may reflect witchcraft beliefs, which hold that wronged relatives may seek revenge by inflicting illness (Konde-Lule and Rwakaikare, 1989).

Ayieko (1998) describes an orphan boy in Kenya who no longer attends school. He believes that his educated parents died of AIDS because members of their extended family, envying them this education, used witchcraft to sicken them. He does not want to be bewitched because of attending classes himself. Young widows in this same community are often encouraged to remarry within the extended family, regardless of the cause of the first husband's death. When their new husbands die, however, the widows are labeled "husband killers," accused of witchcraft, mistreated, and "encouraged" to leave their marital homes. Even when education and shelter are available to children, the AIDS epidemic may deprive them of both through its association with witchcraft.

Researchers may underestimate the role of witchcraft fears in the social aspects of the AIDS epidemic. Anarfi (1992) reports that few people in Ghana took advantage of free testing or returned to learn test results because of the belief that, since AIDS was in any case caused by evil spirits, what would be the point of knowing?

Of special concern to children under 5 is the possibility that they are seen as carrying the curse that caused their parents to become ill or die, since they are closer in time to the event than older children (O'Gara, personal communication).

Beliefs about orphans in general

Traditional, pre-epidemic beliefs that orphans, especially boys, are likely to thrive and crowd-out other sons, has led many to mistreat orphans, and to the differential frequency of fostering girl orphans. Girl orphans not only become "household helps" but are likely to marry and move away and thus "do not pose long term competition for family resources with caregivers' own children" (Ayieko, 1998).

Many families are quite willing to take in children of relatives that have died. For example, the Kenya Voluntary Women Rehabilitation Centre (K-VOWRC) reported that "The majority of the relatives were positive about taking over the extra responsibility of bringing up the orphans. And one uncle said, "Bahati likes being around and held with a cuddle like any other child. I feel I have a duty to take on the role of a parent". (Njoroge et al, 1999).

However some relatives were negative and declined to take over the responsibility as one aunt said "people should carry their own load, my sister is the one who stubbed herself with the knife". Some families blame patients for becoming infection with AIDS and are unwilling to help.

Njoroge et al, 1999 therefore suggest that "Although the extended family kinship system is being stretched to the brim the majority of relatives are willing to give the orphans a home, love and care but financial and material resources remain a hindrance, thus poverty is a key factor." Community variations in the material ability to absorb orphans, and the stress surrounding it, are significant.

Hunter and Williamson note in “Children on the Brink” that “In Africa, despite their poverty, children benefit from...a stronger safety net than in other regions. These include multigenerational families, single mothers living in sub-households, customs for exchanging children among kin, and the sharing of child support and child rearing. Many of these patterns and customs differ in Asia or Latin America” (Hunter and Williamson, 1997). The AIDS epidemic and increasing orphan crisis, however, continues to deplete extended families’ resources. The extended family “is not a social sponge with an infinite capacity to soak up orphans.” (Foster et al, 2000).

Beliefs about household assets

Traditions that require the sacrificing of livestock and other caretaker assets for male funerals deplete the financial resources available for orphan care. Among the Luo in Kenya “one cannot attend to farm work or other income generating activities after a death within the close relative circle until all the rituals are completed.” When this requires waiting for travelling relatives to arrive, the lack of labor “only worsens the already threatened food security of the bereaved” (Ayieko, 1998).

Child-headed households among the Luo of Kenya, also suffer from the traditional demands that, when both parents die, the roof of a house may not be repaired unless the wife was inherited by customary laws and this “causes many children to move into different houses for shelter.”

Many parents fail to make any preparation for their deaths—wills, arrangements for child care, transfer of agricultural and other production knowledge—because of the belief that talking about death hastens it “(Ayieko, 1998). Drew et al (1996) found that only 2% of families in north-east Zimbabwe wrote a will prior to death. Fears of witchcraft make planning for death difficult in many areas of Africa because a person who talks to another about their impending death can be charged with witchcraft (Foster et al, 2000). AIDS-affected children under 5 represent an important opportunity for AIDS prevention. Denial of the existence of AIDS and difficulty discussing subjects involving sexual matters has seriously hampered prevention efforts throughout Africa. Focusing on the need to plan for the care of young children will present both an easier starting point for discussions and the motivation to pursue discussions past the point of denial for some persons and communities otherwise unwilling to confront the reality of AIDS. Bringing to light fears of contagion that interfere with foster placements for young children will provide important opportunities for education about HIV transmission that can help the entire community.

In any given community or household none or all of these beliefs may influence decisions about AIDS-affected children under 5. An assessment process can become a mitigating action for orphans by bringing these beliefs up for discussion and debriefing.

Care for vulnerable children under age 5

At this point, we know very little about how AIDS-affected children are cared for in communities or institutions. Current information on living arrangements and support for young children is reviewed below.

Who is caring for the children?

Table 4 displays data showing who is caring for orphans. With the exception of Zambia, the data are from small studies linked to programs since there are few population based data available. There were no studies that illustrated care specifically for orphans under age five or who was caring for other non-orphaned children affected by AIDS.

Table 4. Who is caring for the orphans		
Country (ref)	Population covered	Caregivers
Rural Tanzania (PerisLucas Urasa, 1999)	Mawenzi Regional Hospital Moshi, Tanzania 297 AIDS orphans	43% =grandparents, 27%= parent? 15%= extended family member 10%=older orphan 5%=community members.
Chicago	4 Chicago medical centers, 340 HIV+ women, 24 of whom died	44%=grandparents 19%= grandparents and fathers together 17%=biological fathers alone and aunts 19%=aunts/or uncles 9%= non-family members 4% = foster care.
Zambia, (Tembo et al, 1996)	National survey	For double orphans 38% =grandparents, 29%= aunt/uncle 25%= other extended family member 1%=older orphan 6%=non-relative
Kenya (Donahue et al, 1999)	35,000 orphans out of estimated 1,500,000 (2%)	64 registered and 164 unregistered institutions
Kenya, Saoko, 1996)	152 households	27% =grandparents 64% =aunt/uncle 7% =older orphan

Programs for AIDS-affected children under 5

Many communities, donors, governments, religious groups and NGOs are attempting to meet the needs of AIDS-affected and other vulnerable children through community mobilization, micro-enterprise development, community-based support, material assistance, payment of school fees, counseling, and residential care. While most HIV/AIDS programs cite coverage for children of all ages and have at least the potential

for benefiting children under 5, program elements designed specifically to meet the needs of this age group are rare.

A search for programs that provide care for AIDS-affected children under 5 yielded eleven examples, primarily of orphanages. These are certainly not the entire universe of programs in operation, but they are all of the programs that were identified via an extensive literature search and networking with health professionals dealing with HIV/AIDS in developing countries. Presumably, there are many children in foster care but few reports discuss programs to support such families. The eleven programs are described in appendix 1.

Two facts at least are of special interest here:

- The current programs are overwhelmingly residential group care programs. The capacity of the 4 orphanages for which enrollment numbers are available is approximately 120 children, a number that represents significant effort, but woeful inadequacy given the numbers of children who need care.
- Almost all orphanages and programs make a great effort to keep strong ties with relatives. However, there have been few resources invested in systematically exploring how communities and families can be helped to provide better care for these young children, or in understanding the roles played by communities, family members, and others in supporting healthy psychosocial development of AIDS-affected children wherever they are resident.

The most striking feature of these program descriptions is the absence of community based programming designed specifically to respond to the needs of the very young. There are a few exceptions, for example a UNICEF/Government of Malawi Care and Nutrition program in which 17 Early Child Development centers have been established by orphan care support groups. These centers also help to integrate orphans into the social structure of the community by including non-orphans. Some centers are preschools; others are community based child care centers.

As more young children are affected by AIDS community engagement in the care of young children will become increasingly critical, since the costs of residential care of vast numbers of children will surely exceed the budgetary capacity of governments hard pressed to manage the epidemic. Decision trees for determining which children can survive and thrive in their communities and which are in absolute need of residential care will be needed to make efficient use of critical, but scarce, resources for care...

Concerns about orphanages

Institutional placement is considered “at best a last resort, to be used only until more appropriate placement can be arranged...because it generally fails to meet children’s developmental needs, including opportunities for attachment and normal socialization. The younger the child, the more likely it is that placement in an institution will impair his or her psychological development. “ (Hunter and Williamson, 1998).

Orphanages are expensive, have limited capacity, and do not meet children’s need to be part of a family and a community. In the Tororo District of Uganda, the ratio of costs to support a child in an orphanage was 14 times higher than support in a community care program (Germann, 1996). Other studies have found ratios of 1:20 or 1:100 (HOCIC,

1999). In 1992 the annual cost of residential care in Kagera, Tanzania was 5.7 times the cost of supporting a child in a foster home (World Bank, 1997).

A study in Zambia (Participatory Assessment Group, 1999) focused on perceptions of the present and ideas for the future in an open-ended approach. It is distressing, if understandable, that the community's solutions to shelter and education problems for orphans were orphanages. An assessment process that aims to lay the groundwork for implementing community solutions without resort to orphanages should anticipate this difficulty.

Suggested Additional Program Options

Program options that have been suggested for care of young children include the following:

- 1) Monitoring the condition of vulnerable children (Hunter and Williamson, 1998)
- 2) Sharing community labor for cooperative day care to free single parents to work (Hunter and Williamson, 1998)
- 3) Changing community requirements and fees for school (day care) and health services to minimize the burden on needy vulnerable families and children (Hunter and Williamson, 1998)
- 4) Foster care by neighbors (Donahue et al, 2000)
- 5) Support of small group homes within children's own communities through a religious body, NGO, or CBO (Donahue et al, 2000)
- 6) Support to child-headed households to enable children to maintain closest remaining relationships and ownership of land (Donahue et al, 2000)

Review of assessment tools for care of vulnerable children

Although innumerable programs, organizations, and many millions of dollars are engaged in the struggle against the AIDS epidemic and all its effects, there does not seem to be a large, accessible literature directly relevant to specific aspects of the care of young orphans. All AIDS-related work bears on their care indirectly, through impacts on finances, health, energy, and time.

A recent report (UNAIDS, 1999) cites the results of a survey conducted by the U.S. National Research Council among 75 NGOs in 6 African countries: Two-thirds identified AIDS *prevention* as a goal, only one-third identified *mitigation* – where care for AIDS-affected children under 5 would fall—as a goal. *Mitigation* efforts have been largely directed to home-based care programs for sick adults; income-generating projects for individual households or to support NGO activities like home-visiting, raising school fees, grief counseling; and, for young children, orphanage care. With so much critical work to do, it is not surprising that not all areas of mitigation have received full attention as yet. Developing an assessment tool for the current status and care alternatives for AIDS-affected children under 5 will be an important first step.

Assessing the care of young children has great potential for linking mitigation and prevention efforts. Planning for the future care of young children brings acknowledgement of AIDS to the fore; knowledge about HIV transmission is an important part of allaying fears and encouraging foster care for young children.

We reviewed assessment tools used in four major studies of HIV/AIDS orphan care:

- 1) UNDP study of orphans in Kisumu and Siaya Districts, Kenya, Ayeiko, 1998;
- 2) NFNC/LINKAGES/SARA research, National Food and Nutrition Commission Ndola District Health Management Team, 1999;
- 3) Participatory Assessment Group for Situation Analyses of Orphans in Zambia : the community response, 1999;
- 4) Save the Children's COPE project in Malawi

Additionally, we obtained information from 10 other studies surveys for which relatively few details were available. The details of these tools are provided in Appendices 1 and 2.

Assessment tools for orphan care range from the very simple, designed primarily to identify appropriate beneficiaries or to acquire basic enumeration data, to multi-stage studies involving stakeholders from household to national levels. Basic demographic information is common to all; the range of topics addressed beyond this depends partly on the degree to which the process was participatory and partly on the focus of the group conducting the survey.

Procedures for collecting data have included household visits, Participatory Learning Activity (PLA) mapping exercises, questionnaires, semi-structured interviews, focus group discussions, workshops, and participant observation. Most studies reviewed used a combination of tools, and there was little uniformity on what information was collected beyond the number of orphans, the identity of caretakers, and orphan school attendance.

Questions addressed specifically to the care of all children under-5 years of age are largely missing from the tools reviewed thus far, except for research conducted by NFNC/LINKAGES/SARA on infant feeding alternatives among HIV-affected mothers.

Some major surveys have elicited data about characteristics of households that affect under-5 children such as the number of meals typical for a day, the occurrence of visits by health workers, and household income. The most specific child-oriented questions involve school-aged children: attendance at school, participation in recreational activities, knowledge of agricultural skills, and, for adolescents, knowledge of HIV/AIDS transmission and prevention.

Also missing are more than passing references to the role child care services might play in providing respite to elderly or sick caretakers and opportunity for income-generating activities or schooling for other child care providers. No assessment tool examined schedules of need for relief from child care work, community resources for such relief, or how freed time might be used.

Both the UNDP study in Kenya (Ayieko, 1998) and the NFNC/LINKAGES /SARA study found that using several contexts for information gathering yielded a clearer picture of results. The household visits and observations revealed discrepancies between participants' original interview responses and daily realities. Many respondents, for example, reported giving vitamins to babies who did not want to eat, but few families had vitamins in their homes.

The Participatory Assessment Group study report makes powerful reading, as did the Ayieko report. The personal stories and comments of older orphans are vivid, moving, and potentially important in facilitating community action. Any good assessment tool should provide opportunity for such stories to emerge. It must be hoped that others will step forward to speak for orphans too young to describe their needs or propose solutions.

Since general assessment tools for orphan care had few questions concerning the care of children under 5, tools were also reviewed that focused on care for young children in similar communities but not explicitly affected by AIDS.

Assessment tools for feeding of young children

Several tools are available to assess feeding practices of infants and young children in developing countries. Quantitative information on breastfeeding practices is collected in most African countries through the Demographic and Health Surveys, and this information can be used as background data on what typical patterns are. A Tool Kit for monitoring and evaluating breastfeeding practices and programs was produced by Wellstart (Lung'aho et al, 1996) and can be used to help design data collection in small scale surveys. Guides for collecting qualitative information on breastfeeding have been produced by Wellstart (Baume et al, 1996) and are being revised by LINKAGES.

An excellent guide to assessing complementary feeding practices of infants and toddlers and dietary practices of children under age 5 is Designing by Dialogue (Dicken, Griffiths, and Piwoz, 1997). NFNC/LINKAGES/SARA will be developing a tool on formative research for HIV and infant feeding based on the experiences studying this issue qualitatively in Zambia, Zimbabwe, and South Africa. These three countries provide 3 different 'scenarios' - one where no MTCT services were available (and the research

was to help design the program); one where VCT and infant feeding counseling was already available (Zimbabwe); and one where AZT and infant formula were being provided to HIV+ women (South Africa).

Assessment tools for health care practices

There are many assessment tools available for assessing health care practices related to young children. WHO has produced a planning guide for selecting and designing interventions to improve health practices (WHO, 1998). The BASICS project produced an Integrated and qualitative approach to planning and monitoring community-based health programs, and Scrimshaw and Hurtado developed Rapid Assessment Procedures for Nutrition and Primary Health Care. The Academy for Educational Development produced a tool for the design of focus groups (Debus, 1995). Additionally, Winch et al (1999) recently published a guide on qualitative research methods for health issues.

Assessment tools of child rearing practices

Since few assessment questions in the studies mentioned above on orphan care concerned the care of children under 5 directly, tools used in assessing child rearing practices in five African countries were also reviewed. Studies of child rearing can offer tools and information categories primarily targeted to young children. Information from studies of the traditional care situation of children under 5 in sub-Saharan Africa is available for the early or pre-epidemic years in 5 countries.

These studies provide important background. In cultures where young children have always eaten only two meals a day, for example, the meaning of this pattern—and willingness to reconsider it—will be different than for those in which more frequent feedings were typical. Conversely, a ready understanding of the importance of stories and songs in language development recommends those activities to program planners.

All 5 studies (Evans, 1997) reported that

- Parental and community goals for children are centered around social and human values: respect, self-reliance, being helpful, cooperative, AND obedient.
- Children under two are usually breastfed on demand, carried child on mothers' backs, and sleep with their mothers.
- When children are weaned, a physical and emotional separation from mother takes place and others in the family and the community begin to play an increasingly important role in caring for children.
- Older children (beginning at age 4) play a significant role in providing care to younger children.
- No particular value is assigned to interacting with infants and young children. Adults do not play with children, at least until they reach 3 or 4.
- Children are taken to traditional healers first, or exclusively, when ill.

An assessment tool for the care of orphans would ideally be referenced to a community's normal, pre-epidemic child-rearing practices whenever possible, with attention to ways to replace whatever has been lost of the locally-normal methods of feeding, stimulating, and shaping young children. Exceptions to this approach might be made where traditions present special danger to already vulnerable children. Some of these exceptions might revolve around the frequency of feeding, the use of modern

health services, and the consistency of caregivers for children who have lost the stable presence of one or both parents and their original household.

Assessment tools for time constraints of caregivers

Children under 5 need caretakers who have time to attend to their needs. Time may be a community commodity that can be targeted to the support of children under 5 without financial strain. No assessment tool reviewed used tools that examined time use or workloads.

Time becomes an issue for many families struggling with the impacts of AIDS. Even before the epidemic, child-rearing studies reported that having the time to prepare food sometimes made the difference in whether little children had three or two meals a day (Evans, 1997).

The research team in Zambia (NFNC/LINKAGES/SARA, 1999) found that most health providers believed that time considerations made replacement feeding for infants of HIV+ mothers almost impossible. The time involved in acquiring extra fuel, boiling water or milk, and cup feeding itself was thought to be prohibitive.

When families have to care for orphans or sick adults, they often lost the time to work at income- or food-producing activities (Kraak et. al, 1999). Caregiving activities such as feeding, bathing, giving medication, and accompanying relatives to clinics or hospitals for treatment drain caregivers of time to attend to young children. Almost all caregivers and volunteers for people with AIDS are women and girls, the same people who have most responsibility for feeding and care of young children.

Time may play a role in children's immunization status and treatment of illness in stressed families. Travel time and waiting time together may mean that a substantial part of a day is involved in any health clinic visit. For elderly or sibling heads of households, this may represent time that cannot be spared from other tasks.

Keeping older orphans in school long enough to achieve literacy is a high priority for many parents and programs. Both adults and adolescents who need to work and children who need to learn to read need the time to do it in. If either are confined to the household to provide immediate care for young orphan children, the long-term household goals will be lost.

Assessment tools for orphan care should look carefully at caretakers' daily and seasonal needs for time, and potential resources for providing it in the form of child care relief by neighbors, visitors, or child care programs.

Draft Assessment Tools for Care of AIDS-Affected Children Under 5

We have developed a draft set of assessment tools that fit into on-going assessments to mitigate the impact of AIDS on communities. Two versions are offered: one short version for use with focus groups, and a relatively complete initial assessment process. Parts of each tool outline can be used independently by communities or research groups already involved in assessing and ameliorating current orphan care issues. The questions and activities proposed can be included within other PLA activities for AIDS-affected children of all ages in general or for the impact of AIDS on communities.

The purpose of these tools is to help communities get a sense of how children under 5 are affected by AIDS at a minimal cost of time and intrusiveness. Since these are only preliminary drafts, we anticipate that as they are used they may change drastically. We also anticipate that every program, every community will want to adapt these and other tools to suit local skills and needs. As the tools are developed further, we will build in algorithms to facilitate adaptation.

Tools for mapping, focus group discussions, time use inventories, semi-structured interviews with AIDS-affected caretakers, and transect walks are presented. The 4 topic areas most critical for the under 5 age group in households are

- Food and feeding,
- health services and health care,
- consistency of caretaker, and
- stimulation.

The draft tools gather information in each of these areas. In addition, questions relevant to assessing community resources and developing community programs are also included.

The tools below are designed for a community group already interested in focusing on the situation of AIDS-affected children under 5. For some communities, this focus will seem too narrow, at least at the beginning of their mobilizing efforts. A focus on under-5s makes sense in humanitarian and development terms: they truly represent the most vulnerable of a very vulnerable group. Any priority ranking based on need or helplessness will eventually make them primary targets of assistance. Community groups using these criteria can be expected to arrive at a focus on under-5s over time.

The first experienced need of community groups, however, is more likely to be for a general triage tool for targeting the neediest households as wholes, and for tools for arriving at program options directed to entire households.

Assessment and Program Planning Tools, the short version

Focus group discussions may need to start generally, with discussions of “What are the biggest problems orphans face?” or “Which orphans are having the greatest difficulty?” From this beginning, groups may focus on issues bearing most closely on the youngest, most vulnerable age group.

Focus group questions on Feeding

- 1) What happens to babies in poor households whose mothers are not able to breast feed them?
- 2) Sometimes poor children who are old enough can beg to get food or go to a neighbor's for help. How do children who are NOT old enough to do this get food?
- 3) What is the community already doing to help young children get food?
- 4) What needs to happen to help these activities reach more children or be more effective?

Focus group questions on Health

- 1) What do you think usually happens when young orphans get sick?
- 2) What problems could make it hard for orphans to get immunizations?
- 3) What could the health clinics do to help with these problems?
- 4) What could the community do to help with these problems?

Focus group questions on Consistency of Care

- 1) How do families with lots of work to do and many orphans to care for manage to arrange to take care of the youngest children?
- 2) Sometimes little children who have lost a parent or had to move away from their homes are very sad or very nervous. What do you think help them feel better?
- 3) In some countries, women get help with getting their work done when they have young children by taking turns watching over each others' children. Five or six women each take all the children for one day each week, then leave their children with the other women on the rest of the days so they can work. Do you think people here would be interested in doing that? What would be the problems?
- 4) Sometimes families with lots of work, many children, and sick adults can manage most of the time, but can't manage just some times...What are the hardest time to provide care for young children? How would the community help in those times?

Focus group questions for Stimulation

- 1) Do you think young orphans and babies are left alone much of the time, with no one to talk to or play with?
- 2) Some communities are worried that orphans may grow up “wild” and not be able to become anything but thieves or gangs. Is this something your community is concerned about? What could help keep this from happening?
- 3) What are the churches in this community doing for young orphans or poor children? What would they need to be able to do more?
- 4) Are there preschools here orphan children could attend? What problems would caregivers have using preschools?

Groups that are able and willing to undertake a more thorough assessment of issues and program possibilities may be interested in parts or all of the following tools:

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The draft assessment tools in this guide provide information to help communities learn about how children under age 5 are affected by AIDS and to help them develop programs to improve the child of such children.

Some or all of the activities shown below can be included, depending on the time and expertise of program staff and community members. Possible data gathering activities include:

MAPPING

FOCUS GROUPS

VULNERABLE CARETAKER INTERVIEWS AND DAILY SCHEDULE

TRANSECT WALKS

Users are invited to subset questions and activities, include them within other participatory learning activities for AIDS-affected children of all ages, or include them in efforts to assess the impact of AIDS on communities.

MAPPING

Mapping exercises can locate and identify a community's most vulnerable young children, those orphaned by AIDS or other causes, as well as other vulnerable children.

Households that have children under five, deceased parents of those children, living parents unable to work consistently, or heavy burdens of care for AIDS-affected individuals must first be identified. The next step, determining which AIDS-affected children are especially vulnerable and why, is complex. In reality, many communities and programs use informal triage sequences to target assistance to the most vulnerable; these data should help make those sequences and decisions explicit and transparent. Criteria for assessing the data and making decisions about assistance, must be based on the community's own priorities in order to lay a reasonable groundwork for later activities.

Communities will have local and unique criteria for the "especially vulnerable" category, but children under five, living in child-headed, woman-headed, and elderly-headed households deserve basic consideration. A wealth/ well-being ranking exercise to determine which households are "poor" may be useful. Keeping the focus on young children, participants should be encouraged to consider that young children may be more or less vulnerable in households of apparently equal wealth, depending on the willingness of caretakers to spend resources on the children.

Mapping Questions

- 1) Number, ages and sex of household members.
- 2) Status of parents of children under 5: living; missing, working elsewhere, resident elsewhere, in hospital
- 3) Category of household head (child-headed, woman-headed, and elderly-headed)
- 4) Poverty level of household
- 5) Caregiving needs in the in the household: For each resident ask:
 - How many days were they able to work or attend school in the previous month? -for those unable to perform one quarter of the time,
 - Are they ill? For how long?
 - What are the caring responsibilities of each individual in the household? How long does each caregiver spend giving care? What activities does each forego to provide care?
- 6) Are any household residents responsible for care of individuals who do not reside in the household? Who are those individuals? What is their relation to the caregiver? Where do they live? Why are they not resident in the household?
- 7) Are the children of school age in school? Why or why not?
- 8) How are the children under 5 related to the other persons in the household?
- 9) Who cares for the children under 5?
 - What are the caring responsibilities of each individual in the household? How long does each caregiver spend giving care?
 - What activities does each forego to provide care?

FOCUS GROUPS

Individuals involved in the mapping exercises become key members of focus group discussions. Focus group questions include questions about feeding, access to health services, consistency of caregivers, interaction/stimulation, and resources for addressing these issues.

Assessing care

Suggestion: For each group of questions, draw a matrix to chart responses of the group. Display the matrix on an easel or on the wall. Enter data as the discussion proceeds. Use it to verify or explore responses. This facilitates data recording and stimulates review, discussion, and ownership by the group.

If participants are reluctant to talk about their own practices, ask about their neighbors, friends, or best practices.

Focus groups may help obtain useful information, but as shown in the NFNC/LINKAGES/SARA work in the Zambia, focus groups on feeding often provided idealized answers, and it was necessary to obtain information on individual children to obtain a clear picture of feeding practices (Piwoz, personal communication).

Focus Group Questions on Food and Feeding

- 1) How are children fed in this community? Who usually feeds each child under 1 (infants), 2 (toddlers), 3-4 years?
- 2) What is each child likely to be fed? Why? How many times a day?
- 3) What should each child be fed? Why?
- 4) How is each child fed? What implements are used? Where does the child sit or lie?
- 5) If the child is held, how is the child held? Is it good for a child to be held while feeding? Is it good for a child to be held at other times? Does anyone talk with the child while feeding? What do they say?
- 6) Does the child play or laugh while eating? Why? Is this a good practice? Why or why not?
- 7) Why are older and younger children fed differently? Could they all be fed the same way? Why not?
- 8) What difference does a child's sex make?
- 9) Who is the best person to feed a child of each age and sex? Why?
- 10) What makes one caregiver/feeder more suitable than another?
- 11) Who is responsible for providing food for children, for the family? What is the role of the baby's father?
- 12) Do all mothers breastfeed? What mothers do not? Why not?
- 13) What happens to babies if they are not breastfed? Are they healthy? Do they survive? Do they have special needs compared to breastfed children?
- 14) What other foods and fluids do mothers give infants? When do they start giving those foods or fluids? Why?
- 15) Should mothers who are ill breastfeed their children? Why or why not?
- 16) Should other women breastfeed the children of an ill mother? Why or why not?
- 17) What happens to babies whose mothers have died? Who cares for them? How are they fed? Who is responsible for their wellbeing? Are they healthy?
- 18) What special needs do they have? Are there many babies whose mothers have died in this community?
- 19) What do people feed babies who are not breastfed? What were the traditions (in your parents time)? What do people do today? What options are available in this community? Explore about different types of milk that are available.

Assessing program options

- 1) Is there a food shortage in some households? Describe the shortage and its causes
- 2) How do very poor people get help with food in the community?
- 3) Are World Food Program or other donated commodities (USAID, DANIDA, NORAD, etc.) available in the community? How often do they come to the community?
- 4) Where can families buy low cost foods for young children? What are those foods?
- 5) Why are those foods good for young children?
- 6) Is there any animal milk or formula available in the community? At what cost? **(a market survey can be done in local stores to obtain these answers)**
- 7) Are there any special complementary foods for children 6 –18 months? Who makes or sells them? How widely are they used, and by whom?
- 8) Are young children well fed in this community? Why or why not?

Focus Group Questions on Access to Health Services

Assessing care

- 1) When should people bring children under 5 to a traditional healer?
- 2) When should people bring children under 5 to to a health clinic?
- 3) Are there other people who give help or provide advice on the care of a sick child (e.g. pharmacy, family member?)
- 4) Who decides when a child should get special care or when consultations should be made?
- 5) Who actually makes the consultation/takes the sick child?
- 6) How much time does each type of consultation take? (break into travel, waiting, service)
- 7) Who cares for a sick child in the household?
- 8) How should a sick child be fed?
- 9) How much does each type of consultation cost?
- 10) Are health services ever provided free of charge or at reduced fees? When or for whom?
- 11) Who decides how much to spend on care for a sick child?
- 12) Are different decisions made for an infant or toddler or preschool or school aged child? Why?
- 13) Are different decisions made for girls or boys? Why?
- 14) If a young child's mother is ill, what care should that child receive if s/he becomes ill?
- 15) Should children who have coughs, fevers, or diarrhea receive immunizations?
- 16) If a child's parent has died of AIDS or TB, should people still immunize him/her? If a mother has died or is sick with AIDS or TB, is the child likely to be infected?
- 17) What keeps people from using health services and immunizations for HIV-affected children? For other children?

*It would also be useful to ask health care providers these questions as well.

Focus Group Questions on Consistency of Caregivers

Assessing care

(In these discussions it is important to explore gender differences and age differences for each issue.)

- 1) How many different people usually look after an infant, a toddler, a 3+ year old in a household that was well-off?
- 2) Who are the best caregivers for infants? Why?
- 3) Who are the best caregivers for toddlers? Why?
- 4) Who are the best caregivers for 3 –4 year olds? Why?
- 5) Do infants, toddlers, or 3-4 year old children need to have one or two main caretakers? Why?
- 6) Should caregivers play with young children? How? Why?
- 7) Should caregivers hold young children? How? Why?
- 8) Should caregivers sing to young children? How? Why?
- 9) Should caregivers tell stories to young children? How? Why?
- 10) Should caregivers talk to or with young children? How? Why?
- 11) Do young children who have lost a parent or had to move around feel more nervous about who takes care of them or about caretakers changing during the day?
- 12) Do people have to give up working in order to take care of young orphans?
- 13) Do older children have to give up going to school to take care of young orphans?

Assessing program options

- 1) Are any neighbors or groups caring for children less than 1 year of age? 2 years? 3-4 years?
- 2) How do caregivers use their time when their children are in group care?
- 3) How old must a child be before a parent would feel safe to leave him or her with a neighbor or in an organized group?
- 4) What would make the child feel safe about such an arrangement?
- 5) What are good features of the group care?
- 6) What features of group care are not good, or not done well?
- 7) What problems do people have when caring for children less than 1 year old? 2 years? 3-4 years?
- 8) What help do people need taking care of other people's young children?

Focus Group Questions on Stimulation

Assessing care

- 1) What needs to happen to make a good life for a 1 year old? 2, 3-4 years old?
- 2) In this community, how is the life of a child less than 1 year like or not like that ideal? A child 2 years old? 3-4? Why?
- 3) When you were young, did adults talk to you, tell you stories and riddles? Do you do these things with your children? Why? Why not?
- 4) Did you have toys to play with; if so, what toys?
- 5) What toys do your children have?
- 6) Why should boys go to school? Why should girls go to school?
- 7) What do you think prepares a child for school?
- 8) What helps children succeed in school?
- 9) Do you think playing, talking and toys are important for children? Why?
- 10) When older children take care of infants, toddlers, and 3-4 year olds, do they talk to them and play with them usually? What do they do?

Assessing program options

- 1) Who are the good storytellers here? Good singers?
- 2) Does anyone locally make good toys?
- 3) Is there a preschool nearby? What are the fees and labor expected?
- 4) What kind of person makes a good caretaker for a group of infants? for toddlers? for preschoolers?
- 5) How big should care groups be for children of different ages? Why?
- 6) How many hours a day should children of different ages be in care groups? Why?
- 7) Are people worried about taking care of young children whose parents have been sick?
- 8) What would make people NOT want to help care for young children?

VULNERABLE CARETAKER INTERVIEWS AND DAILY SCHEDULE

If a purely PLA process is used, this step in information gathering would depend on the felt need of the community for more detailed information. Separate focus groups of adult and older-child caretakers might be able to provide much of this detail when individual interviews are not appropriate. Preliminary interviews with household heads may be important in some cases, to make caretaker interviews more comfortable for everyone. Household heads might be asked for views of the difficulties the community is currently facing.

All adults and children who take care of children under five in the household should be interviewed to provide a complete picture from the perspectives of both young child and older caretakers. Interviews with the principal caretaker should begin with basic demographic data about the household (as shown above under mapping), but move quickly to daily schedules. Caretakers could then be specific about caregiving activities without fear of contradicting any previous statements made in response to more general questions.

Daily schedules: Caregivers would be asked to describe a typical day in sequence while interviewers take notes. This description could then be confirmed with caretakers through a matrix of activities and times, showing multiple activities taking place simultaneously. The specific times and type of greatest demand may be helpful in eventual program design. In areas where workload varies significantly with seasons, a seasonal calendar can be constructed with caregivers as well.

Caregivers might be then be asked the personal forms of focus group questions about food, health, consistency of caregivers, and stimulation, with emphasis on what actually happens in the household as well as interest in personal beliefs and experiences.

TRANSECT WALKS

Using the map of the local community from mapping groups, and information from caretakers about scheduling challenges, community members involved in assessment can walk through the community observing aspects useful in planning interventions. Some of these aspects might be: concentrations of households that might assist each other in OVC caretaking or time-consuming household chores; availability of spaces for child-oriented activities; distance to food and water sources and health services for OVC families; NGOs or church organizations in the area.

Moving to action

Data analysis

While communities will have their own purposes for information gathered and may not feel the need for very specific numbers, it is strongly recommended that enumerations or summaries of information be kept in usable form so they can be shared with other communities. Information taken from multiple communities and consolidated, can form the basis of dialogue and planning with policy makers.

Specific numbers can help communities estimate the number of people or supplies needed to implement program ideas. Specific numbers also create a baseline against which program effectiveness can be measured, which is important both for the community and to potential donors.

Community participants in PLA activities would proceed from these data to problem and solution ranking, choosing an Action Plan Committee and creating a Community Action Plan.

The USAID/Global Bureau is developing a framework and methodology to assist community based programs in monitoring and evaluation. It will integrate information from sectors such as nutrition, education, child development and health, and as such will be especially useful to communities, organizations, and governments focusing on AIDS-affected children under 5.

Development of Program options for Community Action Plans

Communities that choose to focus on improving the **feeding** of children under 5 could consider a variety of options:

- Community creches (sites where infants are cared for together) , babysitting, or rotating neighbor care (elaborated below) to free caregivers for agricultural work or work outside the household to increase income for food
- Growth monitoring and promotion of children under age two
- Community creches to which international agencies (World Food Program), local NGOs, or private individuals can donate appropriate foods and milk/ formula or money for food directly. Young children can receive food directly, and donors have assurance that food reaches children
- Community food baskets that emphasize young children's food (such as fortified complementary food)
- Informing community members about the level of risk mother to child transmission and other needed messages about HIV to prevent abandonment by mothers known to be HIV positive

Communities that choose to focus on **health** issues could consider:

- Organizing transport to clinics or of clinic staff to the community to provide preventive and treatment to areas with high rates of vulnerable children
- An Immunization/vitamin A supplementation day for young children, including assistance to caregivers of children affected by AIDS for transportation or childcare on that day
- Building or renovating space for a health center branch near concentrations of AIDS-affected households with children under 5 with reduced or no fees for young children
- Creating a volunteer rota of transportation or child care help so that caregivers of AIDS-affected children under 5 can take children to health service during severe illnesses or for immunizations
- Increasing awareness of treatment for diarrhea and acute respiratory illness and importance of immunizations for sick children throughout the community through child-to-child programs in schools, public workshops and posters, special training for community health volunteers who can then train caregivers as well
- Increasing awareness of causes of HIV so that young children will not be seen as affected by witchcraft

Communities that choose to focus on **consistency of care and stimulation** issues could consider:

- Creating space and volunteer staffing for community **creches** near concentrations of AIDS-affected children under 5. Volunteers and children can receive appropriate foods and child care during the day so their caregivers can work or attend school. Technical support in early child care for these caregivers may be requested from local NGOs, and foods for the creches can be requested from WFP or other programs providing donated commodities through local NGOs. Local storytellers and singers can be asked to help in the creches, and local craftsmen asked to donate toys.

In order for these creches to be seen as benefiting the entire community, and not just young children, they can become locales for community activities, such as arts or sports centers. Getting older children involved through providing sports equipment (soccer balls, make-shift goals) may be a way to recruit more volunteers for the creches and make the centers more viable. Such community centers could also offer meeting places for caregiver or orphan support groups, counseling, training in parenting skills, or skills training programs for older children.

- Helping AIDS-affected households to organize regular **group home care** for children under 5. Groups of five families can each agree to care for children under 5 on one day a week, leaving the other 4 days available for caregivers to work or attend school. A basket of toys donated or created by the community or older school children could accompany the group of children each day.
- Organizing short but regular **story-hours** for young children at parks, libraries, churches, or other community centers to provide some stimulation for children and respite for caregivers. Volunteers can tell or read stories for young children for an hour or so every week once, twice, or as many days a week as volunteers are available. If successful, this activity can expand to include music, art, or simple games activities with baskets of materials and a blanket or mat to help define the group.

Story hours can create a regular opportunity for isolated or elderly caregivers to meet and share experiences about difficulties and solutions.

- Organizing **volunteer home care** that would permit caregivers to leave young children at a volunteer's home while they attend school or work
- Seeking **training for orphan visiting volunteers** in the issues of children under 5 including feeding and health issues but extending to developmental concerns, discipline, toy-making or whatever issues volunteers and caregivers identify together for young children

Community creches, home care, and story hours can help maintain the viability of the community's informal safety net by providing time for caregivers and volunteers to attend to demands that otherwise conflict with children's needs.

Conclusions and Recommendations

Every nation must be concerned with preserving a living, healthy generation to take it forward to the future. Adult deaths from AIDS are already draining the work force of power and talent. The financial and labor demands of households devastated by AIDS are forcing the next nearest generation out of school. If the part of the youngest generation of all that could survive is wasted physically and mentally in the surrounding pressures, then it is truly difficult to see how countries themselves will survive. As Hunter and William wrote in 1997, "With orphans eventually comprising up to a third of the population under age 15 in some countries, this outgrowth of the HIV/AIDS pandemic may create a lost generation—a large cohort of disadvantaged, undereducated, and less-than-healthy youths. The threat to the prospects for economic growth and development in the most seriously affected areas is considerable" (p.2).

Attention to the needs of children under five and their caretakers can provide a pivot, turning these trends around. Better use of food and health services can liberate already grieving households from the grief of sick and dying children. Better use of time resources can free adults to work and farm; it can free older children to attend school. And it will preserve a generation of survivors much better able to meet the challenges of the post-epidemic years.

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Appendix 1. Institution-based programs providing care for AIDS-affected children

Kenya

- Nyumbani Orphanage and Hospice (CRS/Kenya) Founded as a response to the growing number of abandoned and neglected HIV+ children in Nairobi, Kenya, Nyumbani provides children with a home and nutritional, medical, and psychosocial care. Children live in a simulated village with family-style living arrangements; house “mothers” and “fathers” live and stay with the children 24 hours a day. Elementary and pre-school teachers hold school on site. A nursing team provides medications and medical care. Nurses are always on duty; physicians visit on a regular schedule. Children with one or both parents living but ill at the time of admission are cared for temporarily as parents recover. The orphanage is funded solely by donations.

A study of 104 children cared for at Nymbani (54 current and 50 prior to the study) reported a mean age of 42.3 months at admission, or just over 3 and ½ years of age (Swarzendruber, 1999).

- Leatoto Community-Based Program (CRS/Kenya) This program, established in 1998 by Nyumbani Orphanage (see above), supports HIV+ orphans living with their caregivers in communities in and near Nairobi, Kenya. Nyumbani provides professional oversight, free medical care, some material support (used clothing and blankets), and facilities for monthly educational workshops for caregivers. Social workers and counselors visit families in their homes to offer social support and encouragement; some of the most destitute families also receive a small monetary sum monthly. Leatoto social workers and counselors help HIV+ parents make arrangements for their children in the event of their deaths. Twenty-five children from 22 households were enrolled during June-Aug. 1998; mean age of the children at admission was 57.3 months, or almost 5 years (Swartzendruber, 1999).

Malawi

- Open Arms Infant Home This home, run by the Davona Church in Blantyre, Malawi, provides 24-hour volunteer care for about 25 infants diagnosed as HIV positive. Children are put up for adoption when older.
- The Poverelly Sisters Orphanage This orphanage, run by the Poverelly Sisters in Balaka, Malawi, provides a home for 0-4 year old HIV-infected children from local communities. Relatives of the children are identified and asked to visit them once a month. Relatives are expected to bring 10 Kwacha in cash or an equivalent in-kind contribution to the running of the orphanage.

Zambia

- Kaoma Cheshire Home In Kaoma, Zambia, Kaoma provides care for infants left when mothers die during or shortly after giving birth. The district social welfare office, health institutions, community members and traditional leaders refer infants to the home. A letter of verification from the local traditional leader must support referrals from villages. A relative living within the vicinity must be identified to take responsibility for the infant: weekly visits, in kind or monetary payments for care at the center, looking after the child if he or she is admitted to the hospital. Children are discharged between 2 and 3 years of age. No information on numbers of children or cost per child is currently available.

To help fund daily operations, the home has six rental properties, a small herd of cattle, and a kitchen garden. Funding is available to purchase land for a commercial farming venture, and a guest house is being considered.

- The Muslim Care Orphanage. A private initiative carried out by a business family in Lusaka for the children of their employees who died from AIDS, the orphanage cares for 12 children from the age of 6 months to 17 years. Pre-school and nursery school children are taught at the orphanage by a nursery school teacher. Children live at the home and spend weekend day visits with their extended families.
- Sisters of the Sacred Heart run a day care center for young orphans and other vulnerable children in Mbala. They are supported by NORAD.
- The Bethany Home and Study Centre runs a preschool.
- The Livingstone Street Children Association runs a Child Development Centre.

Zimbabwe

- Ethandweni, the White Water Said Children's Home. Ethandweni is home to 16 boys and girls ranging from infants to teenagers who have become orphans because of the HIV/AIDS epidemic. All are from the Matopo district in the South Province of Zimbabwe.
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- Home of Hope Home of Hope, at the Nyadire Mission Center in Harare, Zimbabwe, cares for infants who lose their parents until relatives are able to take them. Mother and father figures care for the infants; children are gradually introduced to relatives with the goal of eventually returning to the family. A child who is not adopted by age 2 or 3 goes on to an orphanage.

Appendix 2. Assessment tools reviewed

1) UNDP study of orphans in Kisumu and Siaya Districts, Kenya (Ayeiko, 1998). A total of 1101 households, with 2878 orphaned children, participated in this study. Caregivers, orphans, and terminally ill parents were interviewed; 18 focus groups, 9 for caregivers and 9 for orphans, were conducted. Community meetings, interviews and workshops with local leaders and national authorities generated further information.

Household enumeration surveys gathered information about:

- Characteristics of the household: number of orphans per family; orphan age, sex, and relationship to caregiver/guardian (if any); number of siblings in each household (cases of two or three different families of orphans living together in a single grandparent's household were not unusual); age of oldest member of orphan sibling group; number of orphan deaths; provider of current shelter.
- Factors in current care: income and property ownership; number of orphans and other children not in school; frequency of relatives' visits; who has or shares responsibility for household work; main source of advice for orphans.
- Factors for future care: highest educational attainment of household; possession of required agricultural knowledge (land preparation, seed selection/sowing, harvesting and storage, use of fertilizers, use of farm chemicals, raising farm animals, marketing farm produce); types of skills learned from parents.

Focus group discussions (FGDs) with caregivers and orphans generated information on

- Caretakers' FGDs: Traditions, customs and norms that govern child adoption and caregiving in the event of the death of both parents and possibilities for income generation activities to assist poor but willing and capable caregivers.
- Orphans' FGDs: problems facing them and ideas for solutions.

The first Leaders' Workshop brought together researchers, extension workers, district and civic leaders, and other community leaders. The topics discussed included:

Factors in current Care: spiritual and social well-being of orphans; education; health; food security.

Factors for future care: community resources for development and support of interventions; legal and ethical support systems necessary for interventions; sustainability of interventions and support groups; orphans' property ownership and inheritance rights; mobilization of the community for interventions; community strengths and resources; community weakness and difficulties.

The second Leaders' Workshop was organized for village elders, school teachers, church leaders, caregivers, widows and widowers, village AIDS workers, community volunteer health workers and village social workers. Topics discussed included:

Factors for future care: how to involve the whole community, and empower villagers to take the major role in running an intervention; how to identify or appoint a guardian for orphans should parents die without having done so; how to impart to orphans a sense of belonging to the community. Also discussed were the community's strengths and weaknesses, and the customary and government laws that could be used to protect orphans.

Researchers in this study also participated in several general community meetings such as religious congregations, chiefs' barazas, and leaders' conferences to address the villagers on HIV/AIDS and orphan issues. No official data gathering took place at these meetings but researchers credited them with providing critical information: "It was at such meetings where we heard the community members talk about what they were going through and how they were responding to the problems as individual households and as a community. During such meetings, we learnt how the villages discussed the issues amongst themselves, as opposed to what they tell data collectors, and how they respond to conversations with outsiders" (Ayeiko, 1998, p. 4).

2) LINKAGES/SARA Research, Zambia

In Zambiaresearch was designed into community understanding of HIV and infant feeding issues (National Food and Nutrition Commission Ndola District Health Management Team, LINKAGES, and SARA, 1999) . Approximately 65 mothers and caretakers of children under two years of age, mothers' group members, health providers, and community members supplied in-depth information about these issues. Although the extensive interview questions and detailed follow-through about feeding practices in the LINKAGES/SARA protocols do not recommend them for use in the early phases of participatory assessment, the tools provide an excellent guide to the issues involved in the safe feeding of young orphans.

Key informant interviews and focus group discussions with mothers and caretakers_gathered information about:

Characteristics of caretaker, child, and household: household composition; number of families living under the same roof; number of family members living together; identity and age of caretaker; number of living children, age of youngest, infant's birth date, birth weight, growth pattern.

Factors in current care: caretaker's work outside the home, occupation, number of years of education; members of household regularly employed and frequency of payment; weight-for-age; reasons for growth faltering; infant's vitamin A supplementation history and immunization history.

Factors in future care: knowledge and awareness of HIV/AIDS and how it is spread; knowledge about testing and counseling availability; communications around the decision to get tested and sharing the results; attitudes about HIV, breastfeeding, and testing.

Key informant interviews with health providers covered all the HIV/AIDS issues above, and current practices in counseling. Participants were asked about their current counseling practices with regard to: infant feeding; advising women who choose not to breastfeed; antenatal and delivery care; family planning and sick child care; growth promotion and counseling.

Household interviews held during observations and cooking demonstrations gathered this information:

Factors in current care: breastfeeding practices; purchasing, preparation, and feeding of nonhuman milk and thick porridge; household water availability, hygiene, and sanitation; child caring practices and child behavior; foods in the home, food storage, and food security; availability and use of multivitamins; home construction and amenities.

Factors for future care: Caretakers were asked for their opinions, experience with, and willingness to try these feeding recommendations: cup-feeding during the day and night; preparing and feeding infant formula; preparing and feeding cows' milk (including boiling, and dilution with boiled water and addition of sugar for children less than six months); boiling water, sterilizing feeding utensils; exclusive breastfeeding (for children less than six months). Caretakers were also asked for their opinions, experience, and willingness to try the following: expressing breastmilk, boiling and feeding it; cooking with milk (for children older than six months); enriching porridge and *nshima* with milk and different ingredients/foods; increasing the frequency of feeding; giving fruits and snacks; increasing feeding (frequency, quantity, variety) during and after illness; attending monthly weighing sessions.

Two other important assessment tools were included in the household observation sessions:

- A 24-hour food recall by caretaker and
- measurements of the volumes and exact sizes of all feeding utensils

A market survey gathered information on the brands, sizes, prices, and quality (e.g., fortificants, packaging, expiration dates, etc.) of infant formula, liquids and powdered cows' milk, soap, sugar, and vitamins.

Although the LINKAGES/SARA protocol called for information on immunization histories and child care practices, that information was not available in the draft report, beyond a general comment that most children seemed to be active, alert, and well-loved. Researchers believed that caretakers know what to do for young children and want to do it; problems arise when the demands of daily life made it impossible for them to bring knowledge, desire, and practice together.

The LINKAGES/SARAtools are excellent examples of using assessment to inform, and lay groundwork for, keenly targeting programming.

3) Participatory Assessment Group, Zambia

As part of a large situation analysis of orphans in Zambia, the Participatory Assessment Group held mapping exercises and semi-structured interviews with community leaders, orphan guardians, and orphans. A total of 704 people participated in the study. The research was aimed at bringing to light these group's perceptions of the problems, coping strategies, external assistance, and general issues in orphan care.

Thirty-six mapping exercises and focus group discussions created information about:

Characteristics of households: Incidence of households keeping orphans; number of dependants & orphans in households; gender & age characteristics of head of household which keep orphans; relationship (type of relative or relative neighbor) between the orphans and the head of the household.

Factors in current care: number of orphans attending school, distance of school from home; wealth/poverty status of households keeping orphans; access to social services; households' problems and priorities; coping strategies (reducing the number of meals per day, doing piece work).

In addition, *mapping groups and key informant focus groups with teachers, social welfare officers and leaders of NGOs and CBOs* explored solutions to problem most highly ranked in ranking exercises. In problem/solution pairs they were:

Factors for future care: food/employment; health/employment and construction of a clinic; shelter/creation of orphanages; schooling/creation of orphanages that would provide education.

4) Save the Children's COPE project in Malawi

Save the Children/US has developed assessment tools for village use as part of its role in the COPE II program (Community-based Options for Protection and Empowerment) in Malawi. Tools include a baseline survey questionnaire for households, a focus group discussion guide for home-based care (HBC) providers, a questionnaire for interviews with HBC households, and a prevention-oriented questionnaire for interviews with adolescents.

Only information directly relevant to orphan care is given here. Since Save/ Malawi's survey and questionnaire assessment tools cover a lot of ground in detail, subcategories in current and future care are presented.

Baseline surveys and household questionnaire provided information about:

Characteristics of households: total number of people in household (adults/children 0-18); number of orphans; orphan(s)' sex, age, status (orphan, OVC, normal); type of vulnerability (both parents dead, one parent alive, one or both parents critically ill, living in a female-headed or other vulnerable household). Information was also gathered about the characteristics of the household head: age, sex, relationship to OVC, level of education, main sources and time commitment of income.

Factors in current care issues:

Food: number of meals per day; main meal food items; sources of food; OVC and other children's contribution to food and methods of obtaining food; assistance received from or given to community gardens or food baskets.

School attendance: OVC school attendance; highest level attained; type of school; distance of school; responsibility for financial and other support for school; main reasons for lack of attendance; desire to return; problems faced in school; assistance at school.

Household income: main source; main breadwinner; main form of payment for work; income sufficiency; OVC contributions to income; nature and frequency of OVC's income-generating activities; nature, frequency and use of payment; income activities, frequency, and payment method for other children.

Asset Ownership: orphan- or widow-owned assets; property lost; actions to redress loss.

Structured Recreational Activities (SRAs): identity and frequency of participation; reasons for lack of participation; distance of activities from household; organizers of SRAs and after-school sports.

Factors in future care:

NGOs operating in community

Community gardens and food baskets: size, laborers, food quantity, type of crops, seed sources, technical input, interest in starting, ways of operating.

Community knowledge of rights of child, laws, mechanisms.

HIV knowledge and prevention: awareness and knowledge of HIV/AIDS; source of information; identity, frequency, location of distribution of prevention materials; presence of youth clubs; HIV/AIDS training at youth clubs.

Linkages with institutions: presence of social, health, and development workers in the community; frequency of visits from these and their main activities during visits.

Cultural practices: predominant tribes and religions; beliefs and practices about AIDS awareness included in initiation and other traditional ceremonies; sex; rites followed after death of husband or wife; number of chiefs presiding over property loss cases.

Children 5-14 and 15-18 years old were interviewed directly; their contributions to households, school and recreational needs explored. The information gathered about food—frequency, type, sources, and assistance—could give an overall view of food resources available to younger children as well, but otherwise, once again, the 0-5 age group will require its own questions.

5) Other less extensive/intensive data studies

The tools used and type of information gathered by ten other studies is presented here in table form. Less detailed information was available for these studies, but they may help illustrate the kind of work that has been done in the recent past.

Table A1. Instruments used in assessment tools in Zambia					
Reference	McKerrow, 1996a	McKerrow, 1996b	Milimo, 1996.	Poulter, 1997	Tembo and Kakungu, 1999.
Type of instrument used					
Household questionnaire	yes	yes	no	no	yes
Focus group discussions	none	none	community	Community capacity-building team; school teachers	none
Semi-structured interviews	HH Orphans Caretakers	none	Community members	Same as above	All household members 12+ years; all children \geq 11 yrs.
Community meetings	none	none	As above	none	none
Workshops	Community	community	PRA	none	District level officials; villagers and community workers
Other tools	none	none	Observation and testimony	Review of documents	Height and weight measurement for children 0-5

Table A2. Instruments used in assessment tools in Uganda, and Zimbabwe

Reference	Uganda , Ministry of Labor and Social Affairs and UNICEF, 1993.	ZimbabweFo ster et. al, 1992.	Zimbabwe Jackson et al., 1996 a.	Zimbabwe Foster et. al., 1996 b.	Zimbabwe Foster et. al., 1997
Type of instrument used					
Household questionnaire	Yes	Yes	No	No	no
Focus group discussions	None	None	Delegates of Zimbabwe Commercial Farmers Union; male workers; female workers; farm owners	None	Orphans; caretakers; community workers
Semi-structured interviews	None	None	Key workers; groups of children; farm owners	None	Orphans; caretakers; community workers
Community meetings	None	None	None	None	Focus groups
Workshops	None	None	None	None	None
Other tools	Observational checklist	None	Self-administered questionnaire; records analysis; case studies	None	None

Table A3. Information collected in assessment tools in Zambia related to orphans					
Reference	McKerrow, 1996a	McKerrow, 1996b	Milimo, 1996.	Poulter, 1997	Tembo and Kakungu, 1999.
Information collected					
# or % orphans	yes	yes		yes	yes
Type of orphan (mat., pat., both)		yes			yes
Sex, orphn					yes
Age, orphn					yes
Identity of caretaker	yes		yes		yes
Age of caretaker		yes			yes
# or % of households with orphans	yes	Yes			
Poverty level			yes		yes
School attendance	yes	yes		yes	yes
Ability to feed	yes	yes			
Other info	Reluctance to care for orphans			Community priority needs	% or orphans stunted

Table A4. Information collected in assessment tools in Zimbabwe related to orphans					
Reference	Uganda , Ministry of Labor and Social Affairs and UNICEF, 1993.	ZimbabweFo ster et. al, 1992.	ZimbabweJa ckson et al., 1996a.	ZimbabweFo ster et. al., 1996b.	ZimbabweFo ster et. al., 1997
Information collected					
# or % orphans	yes	yes	yes	yes	
Type of orphan (mat., pat., both)		yes	yes		
Sex, orphan	yes		yes	yes	
Age, orphan			yes	yes	
Identity of caretaker	yes	yes	yes		
Age of caretaker		yes	yes		
# or % of households with orphans		yes	yes		
Poverty level	yes		yes		
School attendance	yes				
Ability to feed					
Other info	AIDS awareness/ protection	Discrimination & exploitation	Willingness to care for orphans; access to parental employee benefits	Number of recent parental deaths	Orphan concerns

Appendix 3. Assessments of child rearing in 5 studies in Africa

1) Mali

Dembele and Poulton (1993) conducted *focus groups and observations* in eight villages with Bamanan organizations—women, youth, traditional healers, religious leaders and indigenous change agents—to explore perceptions, beliefs, and attitudes about child care as well as practices. The information gathered included:

Stimulation: Adults talk to children from moment they are born. Between 3 and 6, adults consciously teach language skills through storytelling, questioning, and songs. Many traditional games require, and promote, recalling, memorizing, sequencing and logical thinking skills in preschool-aged children. Traditional tales and riddles help develop intellectual capacity.

Household work: Boys over four expected to care for poultry and animals, learn manual labor such as hiving and mat weaving and cutting thatch for roofing. Girls over four fetch water, bathe babies, pound food, and cook. Children of both genders garden, fetch firewood, run errands, scare birds and monkeys from the field, wash plates, and take care of younger sibs.

2) Malawi

Kalemba's 1993 study used a *checklist of variables for observations and a structured questionnaire for each HH*. One urban and 3 rural areas were surveyed; the total sample was 382 households including 671 children under five.

Stimulation: Mothers and siblings talk to and cuddle young children, and teach them to sit, talk, crawl and walk. Songs, dances, games, and riddles are introduced by the wider community through play with older children and interaction with adults.

Death: Children's deaths are handled with secrecy; it is taboo to talk about infants dying.

3) Namibia

Zimba and Otaala (1991) used *semi-structured interviews* with 136 randomly selected households in ten districts. They collected information about the general background of families, prenatal maternal and child care practices, care during the first three years of life, care practices between 3-6 years, and community goals in relation to child care and development.

Stimulation: Forty-six percent of caretakers reported telling stories to pre-school aged children; 71% asked children to tell their own stories. Seventy-five percent reported teaching children songs about people, animals, birds, religion and politics; 96% report answering children's questions, and 87% said they asked children to describe events that took place in the community. Eighty-two percent reported talking to their children at birth. Twenty-nine percent of caretakers reported talking to, singing with and teaching children traditional dances. Parents said they fostered language development by asking children to get things, name them, touch them, but do not talk about the objects nor describe them to the child.

Once children are 3, contact with their mothers is greatly reduced. In this sample of Uukwaluudhi people, 52% of the mothers reported they had no contact with their over-3 child during the day; older siblings and grandparents become the primary caregivers.

Discipline: When the child had difficulty with a task, 29% said they would tell the child how to do it and have them try again. 18% blamed the child for his/her failure, and a small percentage would simply have someone else do the task.

4) Nigeria

Akinware and Ojomo (1993) used a *household questionnaire* (for fathers, mainly as an entry point into the household), a *maternal questionnaire*, a *child development questionnaire*, and an *observational checklist* with 1507 households in five areas of Nigeria. The *Bayley Mental Development test* was given to some children.

Household questionnaires provided general information on the community. *Maternal questionnaires* obtained information on family composition and demographics, the child's birth,

childrearing patterns and family planning methods. The *Child Development Questionnaire* questioned the mother about the child's nutritional and health history, current health status, physical, emotional and social development patterns, task performance and intellectual development. Information was also gathered on mother's socialization practices, child care options and arrangements and her aspirations for the child. *Observational Assessment Checklists* allowed researchers to collect data on children's physical development, language skills, interactions with peers and adults, types of playmates, feeding habits, relationship to primary caregiver and siblings, and the degree of emotional support provided in the household. Stimulation: Interaction between mother and child occurs primarily in skin-to-skin contact. Fathers begin to carry and play with young children once they are toddlers.

5) Zambia

Chibuye and Osborne (1986) held *structured interviews with adults and with "children who could talk"*. Adults were asked questions designed to elicit info on socio-demographic variables, antenatal, peri-natal, and general care of young children, feeding and weaning practices, and social development and health care practices. Children were asked questions designed to assess their general knowledge of current affairs and the mental and physical development activities they engaged in.

Stimulation: Thirty-one percent of caretakers said they played with children sometimes; 80% said they told children stories and proverbs. Games include hide-and-see, ball games, singing and dancing.

Discipline: Asked how children are taught to be obedient, 60% mothers stated that children are corrected by beating, 30% use reasoning and 7% verbally rebuke.

Death: Deaths, especially of young children, are attributed to witchcraft and little is said about them.