Building a Future
for Families and Children Affected by HIV/AIDS

Designing Care and Protection Programs for Children Affected by HIV/AIDS

I. Introduction

The 1997 World AIDS Day release of ***Children on the Brink*** represented a "wake up call" for the international development community on several levels. First, the report estimates that by 2010, there will be nearly 42 million orphaned children in the 23 countries for which estimates were made, 40 million in the 19 Sub-Saharan African study countries alone. By 2000, there will be an estimated 32 million orphans in these 19 countries, largely due to the AIDS epidemic. In eight Sub-Saharan African countries, 20 to 35% of all children under 15 will be missing mother, father, or both parents. ***Children on the Brink*** portrays the scale and urgency of this unprecedented demographic event, providing a clear picture of the massive impact the pandemic will have on children, families, societies, and economies in Sub-Saharan Africa through the first third of the 21st century (Hunter and Williamson, 1997).

Development and management of systems of care for large numbers of orphaned children is an unprecedented challenge to the governments of heavily affected countries and to the agencies and organizations that assist them. Fortunately, governments, NGOs, communities and families are already developing essential elements of a long term strategy for care and the systems needed to carry it out. This chapter hopes to convey some of the vision of those pioneers so we can support, not hinder, their efforts to successfully construct viable orphan management systems.

The first section of this chapter summarizes health and social problems of children living in a world with HIV/AIDS, both those arising from the pandemic and those arising from the broader social and economic context in which orphans, families and communities found themselves prior to the pandemic's outbreak. The more problematical of these contextual issues are tackled in the last section of the report, which describes future policy and system design challenges facing governments and partners in heavily affected countries.

The second section of this chapter describes the international policy response to the need for systems of care for children affected by HIV/AIDS. The third and fourth sections of the chapter speak to strategy development and systems design on the macro level, and outline the major roles and challenges faced by actors at the two principal levels of orphan "management". Other issues of systems design (providing care for HIV positive children, street children) are also addressed. In the fifth section, the issue of orphan estimates and data development is explored.

The sixth section describes the progress made to date by children, families, communities, governments and partners in finding solutions to these issues. Taking these responses to scale in building systems of orphan management is addressed in the seventh section. Finally, the last section of the chapter identifies additional challenges facing communities threatened by HIV/AIDS.

Development of large scale systems for orphan management and protection is a "work in progress", not an area for which there is a large body of written materials already on the shelf. Most of the published literature on orphans describes the "micro level" management: how the needs of children have been identified and the ways in which communities and families have met these needs. While these responses form the building blocks of large scale systems development, the issues faced at each level are very different.

As a consequence, the material on which this chapter based is derived in large part from site visits and national assessments conducted in 1998 and 1999 to 11 Eastern and Southern African countries (Botswana, Kenya, Malawi, Mozambique, Namibia, South Africa, Swaziland, Tanzania, Uganda, Zambia and Zimbabwe). Each assessment included a comprehensive review of research, generally not extensive, conducted in the country on orphans[1] (Hunter, Botswana, 1998; Hunter, Malawi, 1998; Hunter, South Africa, 1998; Hunter, Uganda, 1998; Hunter, Zambia, 1998; Hunter, Zimbabwe, 1998; Hunter, Mozambique, 1999; Hunter, Namibia, 1999; Hunter, Swaziland, 1999; Hunter, Tanzania, 1999; Hunter et al., Kenya, 1999). Other material is derived from the "micro level" experience of both of the co-authors in developing community, regional and national programs (Parry, 1998; Hunter, 1989; Hunter, 1995).

Several things related to design of national orphan management systems stand out in the national assessments:

1. In spite of years of collection, seroprevalence data are often thin and not well interpreted for planning purposes. In some high seroprevalence countries, governments are trying to suppress new data because they are frightened or dumbfounded by the infection levels confronting them;
2. Well-researched and methodologically sound orphan projections don't exist in many countries. Those that exist are usually for 2000 and are based on very old data;
3. Systematic analysis of orphan projections can alert governments and their partners to the serious social problems they are confronting from the AIDS epidemic. They have been used in several countries (South Africa, Zambia, Swaziland, Mozambique) to mobilize response to the epidemic as a whole;
4. Impact and barrier assessments by sector (education, health, social welfare) are almost non-existent, although the technology is there to do them and they are essential to systematic planning and design (Hunter et al., 1999; Futures Research, 1998);
5. Comprehensive information, such as census or DHS data, on children's health status, family arrangements, and other aspects of their well being are quite limited or dated even in the best resourced countries.

Under these circumstances, governments are challenged with the necessity of developing a response to children's needs that relies on the vision and experience of policy makers and planners rather than technical data and tools. The fact that countries are moving ahead on this is a demonstration of considerable courage, and often requires breaking through layers of denial of the epidemic in order to lay the ground work to protect children for years to come. This chapter consolidates the knowledge that exists in this very new but important field so others are encouraged to proceed.

II. Background

In heavily affected countries, the proportion of children and young people under 15 who are orphans is tripling or quadrupling over pre-infection levels. In eight of the 23 countries included in ***Children on the Brink***, it is estimated that one fifth to one third of all children under 15 will be orphaned (maternal, paternal, or double) by 2000. In all countries where seroprevalence is reaching 20 to 25% -- including Swaziland and Namibia, not included in ***Children on the Brink*** – the proportion of children under 15 who are orphaned will reach this level some time in the

early years of the next century. The extraordinary demographic significance of this figure can be appreciated when it is compare to pre-AIDS levels of orphaning in Sub-Saharan Africa, about 5% for all types of orphans as measured by pre-AIDS censuses and Demographic and Health Surveys (Ainsworth and Rwegarulira, 1993; Hunter and Williamson, 1997). In developed countries, where data on parental mortality is not collected by censuses, pre-AIDS levels were less than 1% and have remained stable because AIDS mortality is relatively low. Data on parental mortality was collected in African censuses for purposes of estimating adult mortality. Not only are orphan levels extremely high and growing, they will remain inordinately high through the first three decades of the 21st century. When infection levels reach the ranges found in Eastern and Southern Africa, they remain high for at least a decade even if incidence levels. AIDS-related mortality will be sustained at high levels through 2020, keeping orphaning levels high for at least another decade (Zambia Central Board of Health, 1997).

Orphaning is only one of the problems – although by far the largest and most pressing -- faced by children in AIDS-affected countries. The prospects of children and young people today have worsened in many other important ways due to the HIV/AIDS pandemic, including HIV infection at birth, in early childhood or adolescence (UNAIDS, 1998; Hunter and Williamson, 1997). Zambia's 1997 NACP report on the status of the epidemic estimated that 50% of all children born in 1998 would die of HIV/AIDS at one time or another in their lives (Zambia Central Board of Health, 1997). In Sub Saharan Africa, one-quarter of all children live in a family where an adult is HIV positive and in need of care and where they are exposed to other infectious diseases, like tuberculosis.

The pandemic adversely affects governments, communities, and families in many ways, making it more difficult for them to protect children, who are threatened in at least seven ways:

1. Infant and child mortality is doubling and tripling (depending on pre-epidemic levels) in countries with high rates of HIV infection;
2. Infant and child morbidity is also increasing because children are living with adults infected by HIV or co-infected with tuberculosis, also increasing rapidly due to HIV;
3. Children and young people live in weakened families where productive adults have died or are dying, and in families that have accepted the responsibility of caring for children left parentless by the epidemic;
4. The communities where children live are weakened by premature adult deaths, increasing twice, three times, or more over levels before AIDS;
5. As a consequence of these changes**,** social support for children and young people is diminishing in heavily affected communities;
6. Many families whose members are sick with HIV/AIDS become impoverished;
7. The remaining proportion of children who are "not affected" are living in societies

Children Affected by HIV/AIDS

- ✔ Worsening Mortality
- ✔ Increasing Morbidity
- ✔ Living in Families Weakened by HIV/AIDS
- ✔ Living in Communities Weakened by HIV/AIDS
- ✔ Receiving Less Social Support
- ✔ Increasingly Impoverished
- ✔ With Declining Access to Health, Education, and Social Services
- ✔ Children's Fundamental Human Rights Are Threatened
  - By Starvation, Illness and Death
  - By Physical, Sexual and Emotional Abuse
  - Their Labor is Exploited
  - They Are Deprived of the Care and Protection of An Adult

> with vastly poorer infrastructure and human resources. Access to health, education, and social services is decreasing as wage earners fall sick and the disease draws off more skilled personnel and resources. In addition, we have no way to factor in grief, horror and resulting social pathology.

As a consequence of these threats to their well being, children and young people face increased risk of death, illness, and starvation due to family food shortages; reduced protection as their family members and guardians die; vulnerability to neglect, abuse and exploitation, including sexual abuse, physical and emotional abuse, and exploitation of their labor; reduced opportunities for education, and increased risk of HIV infection. The pandemic is undermining two decades of hard won gains in achieving the World Summit Goals for Children, and it will have other, far reaching consequences for social structure, economic development, and human productivity. These effects will be felt well into the first three decades of the next century (Hunter, 1998a; Hunter, 1998b).

Children's underlying health was worsening in the most infected countries before the epidemic due largely to increased impoverishment and reduction in social services related to economic adjustment programs through the late 1980s and 1990s. Malnutrition worsened or remained static in 17 of the 22 countries of Eastern and Southern Africa in the last decade (UNICEF/ESARO, 1997). In Botswana, Malawi, Mozambique, South Africa, and Zambia, stunting levels were approaching the upward threshold of 50%, when children become vulnerable to death from other causes (Hunter, 1998a and 1998b). Thirty-six percent of all under 5 deaths in Eastern and Southern Africa are caused in part by malnutrition (UNICEF/ESARO, 1997).

With levels such as these, there is little adaptive margin for such children when their care givers die. The World Bank's study of AIDS-affected families in Kagera, Tanzania, showed that "childhood malnutrition is potentially one of the most severe and lasting consequences of a prime-age adult death…Among the poorer households, stunting…among children under 5 is indeed substantially higher for orphans (51 percent) than [non-orphans]…the difference in the better-off households is even larger…Half of the children who have lost one or both parents are stunted, regardless of whether they live in a poorer household or a less-poor household." (World Bank, 1997: 223-224).

Immunization levels are not high in many heavily affected countries, and have even declined in some countries (UNICEF/ESARO, 1997). Immunization program managers are concerned that health personnel are ignoring protocols to vaccinate infected children, deciding which children are HIV positive based on visual inspection and clinical history (Hunter, 1998, Botswana). Although many resources are being brought to bear on care for HIV positive children, we must also aim at preventing preventable deaths among HIV negative children, increasingly vulnerable to death from other causes as existing protection mechanisms diminish and fail.

III. International Programming and Policy Making for Orphans

Since the beginning of the AIDS epidemic in Sub Saharan Africa, most international organizations and bilateral donors have emphasized prevention to the practical exclusion of programs in care. Two beliefs contributed to this approach: that the epidemic could be controlled or stopped; and that programs of care for the infected or for survivors were "black

holes" or money sinks, and if a donor entered it could never re-emerge. While USAID and other bilateral donors supported pilot programming in several countries, UNICEF took the lead in developing systems for orphan care, planning for long term program integration, and stimulating family and community based responses.

UNICEF was also the first global organization to publish estimates of orphans resulting from increased AIDS mortality. In 1988, ***Children and AIDS -- An Impending Calamity***, a 10-country study in Central, Eastern, and Southern Africa, included the first multi-country estimates of AIDS orphans and the first estimates of the impact of the disease on infant and child mortality ever presented to the international community (Preble, 1990). The estimates were condemned even as they were being developed and roundly criticized after they were made public for vastly overstating the problems facing women and children, although they were supported by empirical data from Uganda (Hunter, 1989). Ironically, these estimates track very closely with U.S. Census Bureau estimates in ***Children on the Brink***.

Although UNICEF formed an international Technical Support Group in 1993 to stimulate programming to scale and gain programming experience in six heavily affected countries, the international policy atmosphere discouraged systematic attention to the issue at this level. Doubt over orphan estimates and fear that attention to children would diminish investment in prevention activities caused orphans to gradually disappear from the international policy making agenda.

Countries, however, struggled on, most notably Malawi and Zimbabwe, where intelligent policy review and systems of community care evolved, unheralded, to exemplary levels (see below). South Africa's considerable commitment to redress social welfare inequities developed during apartheid was harnessed to the same purpose (Lund, F., 1996; DeBeer, 1996, 1998a and b). Though replicable, each of these responses was the result of strong personal leadership. In most countries, programming was limited to running pilots and demonstrations in a few heavily affected areas, falling short of full scale systems design.

Increasingly panicky reports from highly affected countries, coupled with release of ***Children on the Brink*** estimates, revived national and international concern and commitment in 1997. UNICEF is intensifying programming efforts in this area, and is committed to providing leadership among the UNAIDS co-sponsors globally on the issue. In 1998 and 1999, national program responses in at least 20 heavily affected countries will be assessed with UNICEF-UNAIDS assistance. Realization of this goal will require the combined efforts of country governments, non-governmental and religious bodies, the private sector, UN agencies, donors, and the research community in developing programs sustainable for the next two to three decades. USAID headquarters has officially collaborated in one assessment (Hunter et al., Kenya, 1999), and other bilateral donors and other country level partners are always involved.

To encourage cross country sharing and capacity development, UNICEF is supporting regular regional program consultations and sub-regional meetings. The first, held in Uganda in 1998 (UNICEF/ESAR, 1998), included more than 70 representatives from 12 Eastern and Southern African countries, who identified six key strategic interventions:

1. Political will and commitment must be expanded and strengthened through awareness raising and education;
2. Advocacy and social mobilization are equally as important to gain the support of families and communities for care and for long term resource mobilization;
3. Legal framework and legal review can help secure the rights of children and their care givers;
4. Governments must establish or strengthen structures for programming and coordination;
5. Poverty alleviation is critical, and activities are needed at macro and micro levels;
6. Family and community care are the approaches of choice, and must be emphasized and supported in national strategies.

The consultation also identified a preliminary conceptual foundation for orphan programs based on the findings of programs in many individual countries over the past 10 years:

1. Decentralized family and community based responses are the most affordable and acceptable approaches to care for orphans and children left vulnerable by HIV/AIDS. Centralized systems of care and institutional care are a last resort;
2. Community capacity and willingness to care has been documented, but communities must have resources to sustain mechanisms of care;
2. Partnerships with community based organizations are widespread (NGOs, religious organizations, the private sector) and increase their viability;
3. Coordination and strategy building are necessary at all levels and increase the viability of community based responses;
4. Approaches tested at the micro level can be replicated rapidly if appropriate;
5. If included in government development plans, community based programs can be stimulated and linked with a wider resource base;
6. Expanding program responses using a comprehensive country program assessment is an urgent priority in heavily affected countries.

Disadvantage of a Centralized System of Care

- Vulnerable children are too numerous for government to support or monitor directly
- Public welfare benefits reached only a small proportion of vulnerable families and children affected by the epidemic
- Centralized systems encourage dependency
- Not sustainable over the long term
- These approaches professionalize child care unnecessarily, discrediting family and community programs
- Centralization makes systems inelastic, inflexible to local needs, budget driven instead of needs driven, and not tailored to local preferences

Advantage of Family and Community Based Approach

- Encourages community self reliance
- Encourages voluntary and spontaneous links with HIV/AIDS prevention activities
- Recognizes and builds on the reality that PLWHA and affected children get most of their support from families and communities
- Builds on natural family and community roles in protecting children and the elderly
- Social workers and other professionals can focus on serving difficult cases, monitoring, training, and support
- Delivers more benefits effectively and inexpensively
- Fewer children fall through safety nets
- Builds on African preference to maintain children within their families and communities

IV. Strategy Development

A. Strategic Foundation

While it is not possible to change the facts of increased death and morbidity for children in heavily affected countries, it is possible to develop systems of care and protection for children that incorporate substitute social mechanisms for care and mitigate additional suffering. If a strategy is developed to accomplish this, some of the overall damage to the social and economic functioning of future generations may be averted. Strategic actions to mitigate the impact of these trends include:

1. Substitute social protection mechanisms and compensatory measures for vulnerable children must be implemented in the short term so that large scale relief activities are not necessary or are averted for some years to come;
2. Responses to child rights must give first priority in Sub-Saharan Africa to those related to survival and meeting basic needs;
3. Stronger strategic direction is needed to evaluate the extent of coverage provided by largely voluntary mechanisms and the effectiveness of safety nets in guaranteeing the basic survival and protection of very young children and children in child headed households;
4. Health, education, and social welfare capacity in Sub-Saharan Africa must be maintained to manage the pandemic's impact;
5. Sectoral strategies must be conceptualized as development-oriented, although formulated to address unprecedented, large-scale mortality.

Strategy is an overarching, multisectoral plan to meet the needs of large numbers of orphans and other children affected by HIV/AIDS over the next two to three decades. Few countries have it! Classically, a strategy works to cover gaps in services by geographic area or program type, building on data from a situation analysis. The strategy would be linked with goal setting for coverage of community based programs and State safety nets (by age, location, vulnerability), and for well being of children and care givers (measured by indicators like health, nutrition, and school enrollment). Strategy development and implementation are hindered by a variety of political and economic issues, most especially by the distortions in the distribution of wealth, the aging patterns of populations, and cultural and social constraints on resource access (Hunter, 1999). These factors operate to condition global, national and local strategy, and an analysis of them can improve strategic action.

B. Strategic Capacity

Comparison of the numbers of orphans and other children left vulnerable by the epidemic, the availability and distribution of services, and the lack of explicit strategies for support to family and community based responses in most countries suggests that capacity for strategy development is required along several dimensions:

1. **Technical Analyses**. Capacity for making orphan estimates and conducting sectoral analyses to identify demographic and economic impact;
2. **Policy Review**. Comprehensive review of policy and policy barriers for HIV affected children by sector;

3. **Conceptual Capacity**. Intellectual capacity for strategy development and systems design;
4. **Political Support**. Increased support to families and communities for family and community based systems of care and prevention.

1. Technical Analyses. As a preliminary part of a national strategic planning exercise, national orphan estimates must be prepared, either by the Ministry of Planning/Economic Development or the Ministry of Health/National AIDS Control Program (NACP). It is also important for a central Ministry or Central Statistics Bureau to prepare estimates of population impact in conjunction with Planning, Health or the NACP. Since these numbers are highly political, formal estimates are often difficult to obtain and informal estimates can be used instead.

Ideally, each line Ministry will complete a sectoral analysis, estimating the impact of the epidemic on loss of skilled personnel, and on reducing the client base for their services. These sectoral impact assessments should be refined by each Ministry using the latest population data and projections. Most commonly, an impact assessment has been completed for the Ministry of Health, but is also needed at minimum for education and social welfare. Assessments can be completed by any line Ministry, however, and models are available for guiding these types of estimates (Swaziland Ministry of Education, 1999; Barnett and Whiteside, 1996; Roseberry, 1998; Ainsworth and Over, 1992; Drinkwater, 1993).

In addition, line Ministry planners need to conduct a barrier analysis, brainstorming about other effects of the epidemic, ways to become better prepared to meet the needs of children without parents, and to identify the policies and programs that limit access of AIDS affected children to services (see box). For example, child headed households may not be able to access free primary care, education, or social welfare benefits because the household head is under 18 or does not know his or her entitlements. While safety nets may be officially in place, they may be underfunded, understaffed by social welfare professionals, and household heads may be unaware of their existence.

Strategic and Policy Concerns for a Barrier Analysis by Sector

General
- ✓ Developing partnerships among all players
- ✓ Designing a system that is large scale, equitable, and builds on family and community initiative
- ✓ Protection of very young orphans
- ✓ Delivery of services to households with elderly guardians and child headed households
- ✓ Systems that are effective in rural areas

Health
- ✓ Linking prevention and care
- ✓ Monitoring health status of orphans and non-orphans to ensure equity
- ✓ Delivery of appropriate care to HIV positive children
- ✓ Replacement feeding and proper weaning of infants who have lost their mothers
- ✓ Health workers counsel family members on the special needs of orphans
- ✓ Community health services strengthened to provide special care and attention to orphans
- ✓ Linking home based care with care for orphans

Social Welfare
- ✓ Develop family and community capacity to support orphaned children
- ✓ Provide on-going oganizational and psychosocial support to community mechanisms for care
- ✓ Social welfare benefits may be needed by the poor so orphans can be maintained within the family and community
- ✓ Educating care givers and children to prevent abuse
- ✓ Developing community mechanisms to ensure child rights

Education
- ✓ Ensuring access to education as a protection and socialization mechanism
- ✓ HIV/AIDS education in curricula
- ✓ Alternative schooling in heavily impacted districts
- ✓ Replacing teachers who die from HIV/AIDS
- ✓ Role of Early Childhood Development centers

Women/Gender/Property
- ✓ Educating women concerning property and inheritance
- ✓ Community education on child rights

2. Policy Review. Many countries have completed some parts of comprehensive policy development for children as part of the development of National Plans of Action for Children, stimulated by the World Summit for Children. Others have gone much further in codifying law for children and developing child and youth friendly judicial and ombudsmen systems. Uganda's Children's Statute is the most comprehensive and revolutionary of these legal frameworks. Tanzania recently conducted a thoughtful, sector by sector critique of AIDS policy (Kaijage et al., 1999).

The policy assessment determines if policies take the needs of orphans and other children left vulnerable by the epidemic into account. It can also aim to better coordinate policies in different sectors so they have stronger synergistic effects, and to align policies so that they contribute more constructively to an enabling environment for children and families and encourage community based responses. The enabling environment implies that actors at the international, national and local levels are not only committed to assist orphans and other children affected by HIV/AIDS, but that the necessary implementation structures are in place to see that programs are carried out for their benefit. A thorough-going policy review will include many areas (see box).

Areas for Policy Review

Local Policy Review

- Allocation of land and other resources
- Communal gardens or shelters for children
- Sharing resources with the weaker and more vulnerable
- Use of local services by the poor or disenfranchised
- Participation of women and children in decision making
- Protection of women's and children's property
- Credit associations and small business opportunities
- Widow inheritance and mistreatment of children
- Community responsibility for all vulnerable children
- Interventions with harsh or abusive guardians

National Policy Review

- Review of laws, policies and administration in all sectors to protect child rights
- Children's access to resources without adults
- Increasing women's rights, entitlements and protection
- Recognizing legal maturity for women
- Definition of sexual maturity, age of marriage and defilement
- Entitlement and access of vulnerable children to health and education
- Budget restrictions, discrimination, or insensitivity
- Inheritance and protection of property
- Adoption and fostering
- Paternal affiliation and responsibility
- Public education programs
- Grants or other fiscal support to maintain children
- Positive support for communities
- Support to NGOs and CBOs
- Responsibility of the private sector
- Tax breaks to large private sector employers
- Employee rights, insurance and death benefits
- Targeting productive infrastructure to AIDS-affected communities
- Technical assistance to communities
- Support to increase productivity in agriculture or in small businesses
- Mechanisms to coordinating actors and partners
- Donors examine their policies

3. Conceptual Capacity

At the national level, development of strategies and systems require that national policy makers visualize and orchestrate a system in a fresh and innovative way. The meaning of social welfare must be entirely reconceptualized, moving from individual case work to community-driven development of mutual systems of support. Fortunately, most countries are exploring and undertaking this change because of budgetary restrictions in structural adjustment economics.

Policy Development in Malawi and Zimbabwe

Malawi's National Orphan Policy

Members of Malawi's National Orphan Task Force, with advisors from the Ugandan government and NGOs, developed the region's first "Policy Guidelines for the Care of Orphans in Malawi and Coordination of Assistance for Orphans" in 1992. The guidelines are simple and brief, so they can be used to provide program guidance to community groups:

1. **Community based approaches** to orphan care are primary. The government will coordinate service providers to support and enable communities;
2. **Formal foster care** will be expanded as the second source of care;
3. **Institutional care** is the last resort, although temporary care may be needed for children awaiting placement;
4. Hospitals should **record next of kin** so relatives can be traced if children are abandoned;
5. **Birth and death registration** should be revitalised to monitor orphans;
6. Government will protect the **property rights of orphans** and these should be widely published;
7. **Self-help groups** should be developed to assist families with counseling and other needs;
8. **NGOs** are encouraged to set up systems of community based care in consultation with the government;
9. The **needs of all orphans** should be included regardless of the cause of death, religion, and gender;
10. The **National Orphan Task Force (NOTF)** will continuously plan, monitor and revise programs and policies;
11. Government will solicit **donor support** for resources for capacity building;
12. The Ministry of Women, Youth and Community Service is the **lead government body** on these issues.

Zimbabwe's National Orphan Policy.

Zimbabwe's Department of Social Welfare in the Ministry of Public Service, Labour and Social Welfare is the key agency for implementing child welfare policy. Its services have been decentralized to all 58 districts. However, most of the district offices have one social worker, resulting in unrealistic social worker to population ratios. After four years of advocacy by local leaders, Zimbabwe's government worked with partners to draft a national policy on the care and protection of orphans in 1995, but it was delayed in Cabinet because it requires additional resources. Community based care is universally accepted and promoted. The new policy emphasizes:

a. Care and protection of orphans must comply with the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child;
b. Institutional care is a final and temporary resort;
c. Additional human and financial resources (subnational funds) are needed for orphans, as are budgetary increases to cover sustainable health and nutrition programs;
d. Public awareness campaigns are needed on orphans' needs, capacity building in areas of children's rights, and counseling for orphans and caregivers;
e. Guidelines and legal framework are needed to ensure education for all children, including orphans;
f. Government must protect the property rights of orphans by legislative changes and legal assistance in matters of intestate inheritance;
g. The Department of Social Welfare will take lead in the coordination , implementation, monitoring and information sharing under the programme through the Child Welfare Forum at national and sub-national levels;
h. Grass roots implementation is the responsibility of communities, local government, and NGOs.

To support expanded conceptual capacity at the micro level, social welfare training has to be changed to increase the development orientation of professionals and their ability to train family and community members. Commitment to family and community based systems of care also implies "deprofessionalization" and "demystification" of some social welfare, education, and health roles. Coincident with trends in reduced provision of social services due to economic adjustment, the loss of professionals to HIV/AIDS-related causes also requires that communities provide services for themselves. Increased conceptual capacity at macro and micro levels can be encouraged through site visits between countries and through regular cross border meetings of policy makers and innovative community development personnel.

4. Political Support

Advocacy and public education plans are critical to the success of a national strategy. Two audiences are important: the general public and opinion leaders and policy makers. For the general public, advocacy and education have been used by several countries to:

1. Educate the public about the needs of vulnerable children and how to care for them;
2. Increase adoption and fostering and overcome cultural constraints to both;
3. Alert guardians to their entitlements;
4. Encourage communities to care for families and children affected by AIDS;
5. Educate service providers about government policy and the needs of orphaned children;
6. Reduce stigma and discrimination against AIDS-affected families and children;
7. Educate children about the needs of their peers and encourage their kindness and assistance.

Advocacy and education are also important to develop comprehensive government strategies. Even in the most heavily affected countries, it is often important to educate policy makers and opinion leaders who are not in AIDS or public health work about the impact of the epidemic. It may be possible to work through the National AIDS Control Program, or, in some countries, with Ministries of Planning, Finance, and Development to better integrate AIDS in development planning. In many sectors, the presence of orphans will demand a change not only in scale of delivery but in the mechanisms of delivery of services. Advocacy and public education plans may be part of the National Plan of Action for Children. If not, this document can be revised to reflect the special needs of children orphaned by AIDS and other causes.

Governments in several heavily affected countries have been slow to release HIV and AIDS data – and even, in some cases, census data showing the impact of the epidemic on mortality – because they are frightened of the political consequences. No government with the exception of Uganda and Thailand has been successful in controlling epidemic spread, and economic constraints make many policy makers feel powerless to address its consequences through systematic programming. The impoverishment of AIDS affected communities and the relationship between AIDS and impoverishment are becoming increasingly more apparent, even to the untutored observer. These issues are politically sensitive and can be extremely embarrassing to politicians.

Unlike AIDS itself, politically unpalatable because it is linked with sexual behavior, economic distortion, and gender inequities, the problem of orphaning can serve as a entry point for development of political and social commitment to change because it involves the needs of children. Governments also find it easier to commit to impact mitigation programs for surviving women and children than for AIDS-affected adults who are reputedly suffering the consequences of their own sexual behavior. For example, the difficulties AIDS-affected children, families and communities have in accessing entitlements and benefits are forcing some governments to recognize the economic unfeasibility of social welfare or poverty alleviation grant programs. Children orphaned by the epidemic who do not receive sufficient support from their families, communities, or the State will quickly become visible as street children, delinquents, or children in trouble with the law.

While many governments support the idea of community based programming – not just for orphans, but for a variety of health, education, and development interventions – the development of community capacity is a potential challenge to the control of central government because it stimulates resource flows, including information and the ability to access capital, in channels outside the control of political and economic elites. Fortunately, decentralization is an international donor requirement in most Sub Saharan African countries, and political commitment is often easier to build at the local level.

Key Planning Consideraions for a National Orphan Assistance Strategy

Characteristics of Problem	Program Response
20 or 30 Year Life	Long Term
Large Numbers of Children	Large Scale Community Based Systematized Infrastructure Integrated Low Cost Sustainable
Extreme Vulnerability of Children	Protection and Care Programs Essential
Number of Orphans Predictable	Program Scale Is Predictable Over Time and Inputs Can be Planned
Orphan Needs by Age Group Are Predictable	Program Design Can be Deliberate
Project Impact is Measurable	Determine Success and Adjust Programming
Fundamental Demographic and Social Impact	Development Orientation

C. Planning Considerations

1. General Considerations

As the planning process progresses, certain key planning considerations can guide the development of strategy (see box). As mentioned above, the problem has a 20 to 30 year life, so any strategy must have short and long term components (see Section VIII, "Going to Scale""). It will involve the care and protection of large numbers of children, up to a third of all children under age 15. In developing systems of care, strategic thinkers know that they are providing for vastly larger numbers of children than typically provided for by African social welfare systems in the past. Therefore, any response must be large scale, community based, systematic, integrated with existing infrastructure, low cost and sustainable. Also, responses involve care and protection for very vulnerable children, so they must involve a good deal of oversight, monitoring, and review.

It is possible to plan and develop a rational system of protection and care for children affected by HIV/AIDS, although their numbers will be large, because the number of children in need of care and protection will be predictable. Inputs can be specified and planned if governments take the issue seriously in the near future. Orphan, family and community needs have also been described by a large number of research studies (see Section VII). Project impacts are measurable using standard indicators of well being (Section VIII). Most importantly, the strategic orientation of any program should emphasize development, not charity. This will only be possible if sufficient assistance is available to communities before they reach a stage of exhaustion and burn out.

2. Situation Analysis

A situation analysis preparatory to national strategy development for children, families, and communities affected by HIV/AIDS requires information on the numbers and proportion of

children orphaned; their location, their needs for education, health and protection by age and sex; their guardians' status and women's status more generally; and on the distribution and nature of poverty in a country. Although the emphasis is on orphans, information on all vulnerable children is useful, including street children, physically and emotionally abused children, children experiencing exploitation of their labor and sexuality, and children in trouble with the law. Children often move between these categories in response to stress and loss of a care giver's protection. Estimates for these categories are often non-existent or of uneven quality. Data on services and responses needed for planning purposes include their characteristics (community based or institutional), location, sponsorship, networks, and linkages and collaboration among providers. The nature and sources of data needed are explored in Section VI below.

Ways to "Prevent" Orphans

- ✔ Reduce Births
  - Continue/intensify family planning education
  - Encourage directed counseling for HIV+ women considering pregnancy
  - Make family planning devices widely available, including barrier methods to prevent HIV transmission
- ✔ Prevent HIV transmission
  - Make infection rates widely known
  - Make counseling and testing widely available
  - Provide widespread STD diagnosis and treatment
  - Encourage sexual behavior change
- ✔ Support PLWHAs to live longer
  - Reduce discrimination and stigma
  - Ensure access to medical care
  - Encourage good nutrition
  - Reduce stress, including concern about surviving children

3. Linking Prevention and Care

As a first part of a strategy development exercise, participants must be challenged to link prevention and care by understanding the three principal ways to "prevent" orphans: by reducing births, hence reducing the numbers of children who could become orphans; by preventing HIV transmission; and by supporting persons living with HIV/AIDS (PLWHAs) to live longer. When these connections are acknowledged, drive for effective prevention and reduced stigma and discrimination must be built. Prevention programs in several countries are attempting to motivate conservative sexual behavior by pointing out the consequences of multiple partner behavior on surviving women and children.

V. Design of Orphan Management Systems

A. Management Structure

In addressing issues of "orphan management", at least two levels of response are involved: the macro (national and regional) and the micro (family and community). In the past, micro level responses have been viewed as the genesis for macro level responses. In fact, while there is a purpose to piloting a variety of responses in the early stages of program development, enough is now known about the necessity and pragmatism of family and community programs to state that they are the preferred mechanism for local management. It is more important now to specify roles, responsibilities and challenges at the higher levels of the system so that widespread replication can be facilitated by actors with broader authority.

As in any management system, the concerns at the macro level are substantially and qualitatively different from those at the micro level, and each level must be clearly separated and defined to develop a satisfactory management system (see box). Fortunately, three countries that have accomplished this, Malawi, Zimbabwe, and South Africa, are moving forward with strategic

systems development and can serve as models for other countries that are less advanced. Tanzanian policy articulates such a system, but it is not widely implemented (Tanzania Department of Social Welfare, 1994).

In the "model" countries, strategy and policy development was coordinated by a central, multisectoral body composed of responsible government and NGO (including church) actors. The central body is replicated at regional, district, or provincial levels and at local levels. The NGO community is a full partner with government in strategy development as well as in the provision of social services (including health, education, social work) and community development activities. NGOs have a considerable network of services and collaborate to produce a coordinated, rationalized system of response to increase equity, access and availability on a geographic basis and improve program quality. Following strategy development, coordinating bodies can also conduct policy review, coordinate service delivery, integrate their findings and activities into local development plans, monitor and evaluate program implementation, review program quality, and provide training.

Malawi's National Orphan Task Force implements programs through the District AIDS Coordinating Committees and Village Orphan Committees, and organizes multisectoral planning that includes NGOs and religious groups. While Malawi's national system is the official responsibility of the Ministry of Women, Youth and Community Services, district and local committees are the coordinated by the Ministry of Health's National AIDS Control Program. The findings of the District AIDS Coordinating Committees are included in District Development Plans.

Zimbabwe has a National Child Welfare Forum with branches in all regions, many districts, and in villages organized for community care. Zimbabwe's Children's Protection and Adoption Act, still under review, recommends that the Child Welfare Forum becomes a statutory body. It also promotes the creation of a Child Welfare Fund which is intended to be a basket fund administered by Department of Social Welfare but will have financial inputs from all child related organizations. The Child Welfare Forums are incorporated into the formal government social welfare system so that they can refer especially difficult cases to professional help and community work can be monitored and improved by social welfare officers with formal training. Social welfare officers provide communities with organizational assistance when they wish to develop orphan committees.

Roles and Responsibilities in National Systems of Care for Children Affected by HIV/AIDS (Malawi, South Africa, and Zimbabwe)

Central, District, Local Government	**NGOs Churches**	**Family and Community**
Leadership	Training for families and communities	Provision of care
Stimulating collaboration	Capacity building	Mobilization and coordination of resources
Setting standards and guidelines using consultative process	Material support	Prevention of abuse, neglect
Monitoring community based groups to ensure child rights are protected	Provision of institutional care	Counseling for children, guardians
Handling cases requiring legal procedures	Mobilization of resources required by communities	Collective mutual support (labor, child care, credit, microenterprise farming and food security fund raising)
Helping communities obtain specialized resources		

In South Africa, the Ministry of Population and Social Welfare's pilot for orphan care in the KwaZulu-Natal Province, the Children in Distress Project (CINDI), has a steering committee that coordinates local services provided by community based organizations, NGOs, government social welfare officers, hospitals and home care agencies (DeBeer, 1998). Botswana's local development structure includes multisectoral child welfare committees organized through local government, but these have not been fully mobilized to provide assistance to orphans.

Zambia has local coordinating committees in some areas that include all public and private sector players, but does not have a central coordinating body. The local committees coordinate assistance, and develop referral mechanisms and systems to identify needy children and families. Uganda had an active national coordinating body, but its responsibilities have been devolved to the District level. District Development Committees create plans of action for children and also have the responsibility to raise and allocate tax monies for their implementation.

B. Developing Rationalized Systems of Care

The processes of strategy and policy development in Malawi and Zimbabwe were linked with development of a managed, rational system of care and referral that supports community based initiatives. These systems were developed over a period of several years, and involved two essential ingredients:

1. Recognition, by government, that it would be unable to manage the child protection and care requirements of all orphans and vulnerable children as a consequence of the AIDS epidemic;
2. Commitment to cooperation and collaboration of all actors to support community development and capacity building in order to provide care and support services for families and children affected by HIV/AIDS.

The partners in these systems consciously acknowledged that formal social welfare, health and education systems established and developed through many years of experience prior to the epidemic would have to be fundamentally and conceptually revised because of the impact of the AIDS epidemic. Such recognition was not easy for any of the partners because it involved reconsideration of their traditional roles and responsibilities in child protection.

If decision making criteria for systems design are not explicit, the shape of the system may develop on its own as a consequence of poor resource allocation. For example, institutions, because they are visible, often receive too large a share of government resources relative to the number of children for whom they provide care. This reduces the proportion of resources available to other options for care, especially family and community based care. Also, financial safety nets or grants may receive an inordinate amount of attention but provide assistance to relatively few families and be extraordinarily difficult to administer and monitor as the number of potential beneficiaries grows. If grants are provided, they might be provided through local authorities, NGOs or CBOs on a capitation basis to reduce administrative costs. At least one government is now considering this alternative.

C. Responding to Changing Social Conditions

Due to AIDS and other causes, the situation of vulnerable children has changed dramatically. Changing background factors include increased war and conflict, increased HIV/AIDS, increased poverty, more urbanization, changing governance (increased corruption, democratization, and decentralization), devolution of responsibility to local levels without resource allocation, population changes, increased unemployment, and adverse environmental conditions, such as drought. In many countries social welfare systems designed to address the needs of relatively few numbers of vulnerable children who fell outside systems of family care are now faced with serving very large numbers of children. Systems needed and the conditions under which they operate have changed radically in a relatively short period of time.

Changes in System Characteristics in Heavily Affected Countries[2]

Systems Prior to HIV/AIDS	Systems in Heavily HIV Affected Countries
Children	
Social welfare provides for disabled children, children in trouble with the law, some street children, few orphans, adopted and fostered children	Integrated systems of care are needed for many more orphans, abused and neglected children, more street children, adopted and fostered children, child headed households
Families	
Most vulnerable children are cared for by families	Families are less able to absorb vulnerable children
Strong families exist	Families are weaker
Communities	
Customary law/authority is accepted	Customary law/authority is weaker
Churches have charitable activities	Churches have community development and outreach services
NGOs not numerous or active	NGOs are more active, have a larger role, and are increasing in number
Institutions are small in number	Institutions are small in number
Village committees are not active in this area	Village committees for children are better organized
Public awareness low	Public awareness high and growing
Civil society is unconcerned	Civil society cooperative, active
Governments	
The outreach of social services is fair	Social services are insufficient
Programs from each of the sectoral ministries are vertically administered	Greater decentralization and program integration by Ministries
Partnerships with communities and NGOs weak	Partnerships with NGOs and local committees growing
Government expects to care for vulnerable children	Government expects communities to provide care
Economies and resources fairly strong	Economies weakened; fewer resources
Donor resources to governments	More donor resources allocated to civil society
No social safety nets or poverty alleviation programs	Some social safety nets and poverty alleviation programs in place but underfunded

D. Systems Components and Levels of Care

Countries faced with the prospect of developing a rationalized system of care and protection for vulnerable children must optimize at least three dimensions of the system: financial feasibility, availability of services and personnel, and acceptability. To optimize financial resources, available services and personnel, and financial feasibility, it is understood that the foundation of a system of care is care provided by families and communities. While this has always been the case in the past, fewer children were vulnerable. This emphasis also maximizes acceptability, at

least as far as is known from surveys of families and communities, who typically report their preference for maintaining children within normal systems of social support (McKerrow and Verbeek, 1995; McKerrow, 1996). However, most also report that they will need financial and material supports, including access to basic social services for their children, because of two factors: extreme underlying poverty, and the need to provide for additional children within the same resource base.

A certain proportion of children will fall outside these two sources of care, and must be provided for by institutions, including orphanages, children's homes, and remand centers. In addition, children will need temporary shelters, where they can be provided care while in transit between one permanent form of care and another. For example, children leaving family based care may receive support at a street children's shelter or feeding center while they are rehabilitated for placement in another family or in a community care program.

If the system is explicitly conceptualized as a system, emphasis and investment are distributed proportionate to the number of children needing each type of care. Referral mechanisms are needed to assist children moving from one part of the system to another. Support to family and community care is viewed as a "preventive" intervention because it functions to maintain children in the most "normal" environments possible. To the extent that children fall through these levels of care, then preventive interventions are not functioning well.

The chart on the following page shows an approximate distribution of children within a typical system of care in a developing country heavily impacted by HIV/AIDS. The estimated proportion of children cared for by each source of care shown in the third column is somewhat arbitrary and will change over time as mortality from the AIDS pandemic advances. However, even in a very advanced epidemic, an estimated 55% of children will still be cared for within some form of family, while 35% of care will be provided by community organizations at some level of formal organization. Institutions at any time will provide care or at least shelter for no more than 5% of all children due to fiscal and physical constraints, i.e., the number of places within institutions, while some 5% of children will be in transit, assisted by temporary forms of care.

Table of Models and Options in a System of Care for Vulnerable Children[2]

Model/Option	Responsible Party	Percent of Vulnerable Children	Inputs and supports needed
System as a whole	Government and partners	100%	Legal and policy framework Conceptual base Referral networks, monitoring, identification
Family Based Care	2 biological parents 1 biological parent Extended family No parents/child headed households Formal foster parents Adoptive parents	55% .5 to 1% (with formal adoption)	Free access to basic social services Psychosocial support and monitoring Government assessment and monitoring
Community Care	Village Committees Local government Volunteers Community based organizations (CBO) NGOs Religious organizations Private sector	35 %	Management training Financial and material support Training in psychosocial counseling Child rights training Monitoring and evaluation Awareness raising Advocacy
Temporary Shelters	Street children shelters Feeding centers Places of safety	5%	Management training Financial and material support Psychosocial counseling
Institutions	Orphanages, children's homes Hospices Hospitals Home based care Remand homes Jails Boarding schools	5%	Facility construction, equipment Guidelines, policies, standards Awareness raising Fostering and out-placement Counseling Community visiting CRC training Government assessment Monitoring and evaluation Fund raising skills Networking and outreach services
Social Safety Nets Poverty alleviation Child grants Disability grants Pensions for elderly Free health care Free schools Employment training Income generation Credit schemes	Government and partners	1 to 10% of all children need grants 100% need primary health care and primary school	Ministry Support: Finance Social Welfare Health Education Labor, Education Labor Private sector

E. Targeting Vulnerable Children

HIV/AIDS increases the number of vulnerable children, including orphans, because of the loss of parents, guardians and productive adults to epidemic mortality. The box below provides a preliminary conceptual framework in which to place children, not all of whom will be equally vulnerable. The vertical axis describes vulnerability as "high" or "low", while the horizontal axis describes the number of children The largest number of highly vulnerable children are in the upper left hand corner, and include very young orphans, orphans with disabilities, orphans with elderly guardians, and children in female headed and very poor households. Also highly vulnerable, and very visible because of that vulnerability, are HIV positive children, street children, child sex workers and orphans in child headed households. However, these are fewer in number than children in the left hand box. For example, while a great deal of concern is expressed for HIV positive children, globally they represent only 1.7% of children affected by HIV/AIDS, while orphans represents more than 98% of affected children. Children who are highly vulnerable are likely to need the most safety nets and protection. Children in poorly-resourced institutions are in this category because in many cases, their basic rights are not protected (Ahmed et al., 1999). Children who are less vulnerable are shown in the bottom row of the chart. They include orphans and children with both biological parents in stable families of reasonable means.

Number and Vulnerability of Children Needing Care and Protection

	Number of Children HIGH	**LOW**
	Very young orphans Orphans with disabilities Orphans with elderly guardians Children in female headed and poor households	HIV + children Street children Child sex workers Orphans in child headed households Children in under-funded State institutions
	Orphans in stable families of reasonable means	Children in stable families of reasonable means both parents Children in well-resourced institutions

The left axis should read "Vulnerability" with High (for the top box) and Low (for the bottom box)

Children move between boxes – levels of vulnerability – depending on changes in their life circumstances. The AIDS pandemic is functioning to increase the number of children in the upper boxes, children who are highly vulnerable. The success of preventive interventions will be measured by the number of children in the upper right hand box, those who are most vulnerable.

VI. Data Development

A. Orphan Estimates

Orphan estimates may come from one or several sources, including a country's National AIDS Control Program (often assisted by UNAIDS), special studies, or from ***Children on the Brink***. Estimates for a given country can vary widely, depending on whether they include:

1. **AIDS orphans** or **orphans due to all causes** of death;
2. Orphans who are **maternal** (mother dead), **paternal** (father dead), or **double** (both parents dead). Maternal and double orphans are estimated from maternal deaths, and these estimates are most common. However, as a rule of thumb, paternal orphans are often as numerous as maternal orphans, and in many cases are in fact double orphans because they are abandoned or their mothers die soon after their fathers.
3. **Children under 15** (the demographic cut off) or **children under 18** (the legal cut off in many Sub-Saharan African countries);
4. Orphan estimates also vary by **time period**. ***Children on the Brink*** includes the only projections of orphans through 2010.
5. Orphan estimates can be cumulative (all orphans since the beginning of the epidemic), or represent totals at a given time.

It is important to determine what types of orphans are being included in an estimate and to make careful comparison of orphan estimates. They can then be presented to a national body or steering committee for review so official consensus is established.

Why Paternal Orphans – Children Whose Father Has Died – Are Vulnerable

- In patrilineal groups **when a child's father dies, the child is in fact a double orphan** because the mother is not living with the father, is sent away or leaves to remarry elsewhere.
- Often, both parents are infected, which means that **the child will eventually become a double orphan**, that is, with both parents dead
- Children **over the age of 5 need the cash support** most often provided by fathers for education and health care
- The **vulnerability of families and communities is related to the overall number of adults and children living**, so that a community with large numbers of single or double orphans may have reduced productive capacity

The methodology used to estimate maternal and double orphans is based on female mortality. The number of women expected to die of AIDS or other causes is multiplied by the number of children these women would have had, based on age-adjusted fertility rates, to yield the total number of orphans. HIV positive children are subtracted, and the number is also adjusted for other cause of mortality. Paternal orphans are estimated from census-based rates proportional to maternal and double orphans. The number of paternal orphans, children who have lost their father, will be at least twice the number of maternal orphans (children who have lost their mothers). The ratio may be higher in earlier years of the epidemic because men tend to contract the disease first and transmit it to their female partners. The proportion of children who are double orphans will grow as the epidemic deepens and more female partners die.

Although demographers generally prefer to estimate maternal and double orphans for methodological reasons, the number of children who are paternal orphans is also important. Paternal orphans may be *de facto* double orphans (missing father and mother both) due to the high proportion of female headed households in the country (47% in rural areas and 29% in urban). Orphan estimates do not include parents who are absent from the household but are not dead although non-resident parents may not provide support.

The interaction of tuberculosis and HIV infections has created a resurgence of tuberculosis, and cases have quadrupled in several countries. HIV is progressively eroding the gains made by tuberculosis control programs in all Sub Saharan African countries prior to the AIDS epidemic. TB now clusters around the sexually active age group because of its association with HIV

Comparison of Orphan Estimates

Source	Year	Time Period	Orphan Ages	Cause of Death	Definition	Countries	Totals
UNAIDS	1998	Cumulative Since Pandemic Began to end Of 1997	Under 18	HIV/AIDS	Maternal (mother) Double (both parents)	All Countries with AIDS data	8 million end of 1997
Children On the Brink	1996	Cross-Sectional End of 1990, 1995, 2000 2005, 2010	Under 15	All Causes	Paternal (father)	23 Total 19 African 4 Other	35 million 2000 40 million 2010
African Census Data	Various	Cross Sectional 1960's to 1990's	Under 15 Under 18	All Causes	Maternal Paternal Double	Various	NA
DHS Data	1980s 1990s	Cross-Sectional	Under 15	All Causes	Maternal Paternal Double	Various	NA

infection. The tuberculosis epidemic increases treatment costs and makes disease control efforts much more difficult. As a result of this interaction, HIV-related deaths in adults may be even higher than that projected for AIDS alone, with obvious implications for orphan rates.

Two organizations in the world make multi-country estimates for orphans: the U.S. Census Bureau (in ***Children on the Brink*****)** and UNAIDS. They work closely on AIDS estimates, meet frequently to consult and confer, and are aligning methods and reporting to reduce confusing discrepancies. The highly disparate estimates produced by application of different criteria for defining orphans and making estimates (see box) has created a great deal of confusion about global estimates.

Although the numbers vary widely, when they are compared on the same criteria, they are very similar. For example, UNAIDS reports the cumulative global total of maternal and double orphans as 8.2 million for the end of 1997, but ***Children on the Brink*** estimates 35 million maternal, paternal and double orphans in 2000, seemingly irreconcilable numbers. However, of the latter number, 15.6 million are maternal and double orphans. A large proportion of these are not AIDS orphans (about 50%), so the estimate for AIDS orphans is about 7.8 million. If orphans who are no longer under 15 and those from countries other than the 23 in ***Children on the Brink*** are subtracted from the UNAIDS estimates, roughly comparable figures are achieved. The exact comparison has not been made by either organization because they are currently resolving differences in their calculation methods and models.

B. Data Development

Typically, the information needed on children, care givers, and their families for a thorough situation analysis will not be complete. National data or estimates for orphans and other vulnerable children are usually limited, unavailable or outdated. Prior to the AIDS epidemic, these groups were not numerous and hence not a major concern to governments, and so little

effort was made to collect information. Data on the geographic distribution of vulnerable children and on the distribution of services are also quite limited.

Data on orphans have been collected in the national censuses of several countries, including Kenya, Uganda, Tanzania, Zimbabwe, and Malawi. Censuses have the widest geographic scope of any data and 100% coverage, although their data are typically "thin" in that not many details are collected and household level analysis has not been done. Where possible, it is crucial to encourage country officials to collect data on the orphan status of children during the next round of census taking, on or after the year 2000. This is not difficult to do if undertaken early because it can be demonstrated that the problem is of critical concern to national policy makers, that many other governments are already collecting such information in their censuses, and that the additional data needed is minimal. Marginalized children or families, such as street children or homeless populations, may not be fully enumerated by census takers.

Demographic and Health Surveys are conducted in many African countries every two to four years with the sponsorship of USAID. The household schedules from these surveys usually indicate if a child's parents are living or dead. Until recently, however, only households with child-bearing-age women (15 to 49 years old) were included, which means that orphaned children, many of whom reside on their own or with elderly guardians, were excluded. For this reason, orphan estimates made using DHS surveys taken prior to 1999 underestimate the proportion of children orphaned by about half.

In 1999, DHS instruments and procedures were revised to include all households with children under 5 years of age regardless of the presence of a care giver or guardian. DHS surveys will now include households headed by children or elderly guardians. Also, health, immunization, nutrition, education, and other data will be collected on all children in the household, whereas formerly this data was collected on biologically related children only. DHS are not complete count surveys, but their samples are usually nationally and regionally representative. Unfortunately, coverage of marginalized children and families may also be limited for the same reasons it is in censuses.

In some countries, special surveys or estimates had been made by universities or for poverty monitoring and alleviation. Several of these were quite extensive, and are a valuable resource for current data on children and families (Zambia Central Statistical Office, 1997). UNICEF and its partners in 60 countries are collaborating to conduct surveys of country progress toward World Summit Goals for Children and will have results by the end of 2000. These Multi-Indicator Cluster Surveys (MICS) are "mini-DHSs", an invaluable update on children's status.

Registrations and enumerations of orphans and other vulnerable children collected by local authorities and communities is a popular way to mobilize communities for action. Community members are trained to collect, analyze and maintain their own data as the basis for targeting assistance to vulnerable children and families. This data are usually more complete than census or DHS data, but are often highly variable and unreliable. Neighboring communities in Malawi reported 50% and 6% of their children to be orphaned respectively, reflecting the communities' perception of vulnerability rather than demographic reality.

Malawi and Uganda both undertook national orphan registrations in the early 1990's, and both reported that their experience was "disastrous" (Kalemba, 1998):

1. The registations were too costly to administer on a national basis;
2. The registrations raised false expectations for assistance by communities;
3. The numbers produced were wildly variable and unreliable as a basis for national orphan estimates;
4. Registrations could not be maintained or updated because communities saw no advantage or result to doing so.

Both countries abandoned the effort, and now recommend registrations in small areas or pilot registrations for specific assistance programs. They also recommend local registrations by village orphan committees rather than data collection by a regional or national authority (Kalemba, 1998; Hunter, Malawi 1998; Hunter Uganda 1998).

For the future, cost and quality data are vital in developing long range plans and strategies. At present, they unavailable from most organizations except international NGOs, whose programmes are relatively expensive to administer. Data on quality of services and their effectiveness can also be critical for chosing between alternative forms of care and developing strategies for improving long term programming. Investment data describes the contribution of various sectors to orphan care. It is important to estimate the voluntary contributions of families and communities in order to appreciate their commitment, value their work, and persuade policy makers to support their efforts. One way to do this is to estimate the cost of maintaining all orphans in institutions, or to estimate the cost of paying a substitute care giver in the home were it possible to hire one. This data should include both cash and in kind contributions in order to fairly represent the balance of investments and evaluate their sustainability.

Orphans and Care Givers In Swaziland, 1999

- ✔ Siblings should be kept together
- ✔ Children need to stay in their own homes and communities for continuity and security
- ✔ Many children are responsible for survival
- ✔ Many children are forced to drop out of school
- ✔ Care givers are often elderly women
- ✔ Income generating projects are needed
- ✔ Psychosocial counseling should be continuous
- ✔ Dying parents should know their status to prepare their families for death
- ✔ No monitoring system to prevent abuse
- ✔ Work through traditional structures
- ✔ NGOs and churches provide most of the aid
- ✔ Support to families is self identified
- ✔ Support to families is urban biased
- ✔ Coordination and cooperation of support systems is not strong
- ✔ Leadership and policy is urgently needed
- ✔ Situation is disastrous because support systems are fragile

VII. The Response

A. Children

HIV/AIDS creates many demands and pressures on children and their families. The findings of a 1999 survey in Swaziland on the problems faced by children (see box) are typical of all the HIV affected countries in Eastern and Southern Africa that have conducted orphan assessments (JKT Associates, 1999; Namibia Ministry of Health and UNICEF, 1997; Hunter 1989 and following for country-specific references). Children are pressed into service to care for ill and dying parents and relatives. They are removed from school prematurely to help with household and farm chores, replacing adults who have succumbed to AIDS. They are pressured into sex to help pay for school fees their families can no longer afford, or to help support younger brothers and sisters. Girls are married off at an early age to reduce pressure on their families. Sexual abuse is growing in countries where it has been documented (Ahmed et al., 1999; Shinkinga, 1998).

Often, children are moved from relative to relative as the shrinking number of adults in the family attempt to provide care for an increasing number of orphans. Finally, when families exhaust their resources and coping capacity, children end up living on their own or on the street. As the epidemic progresses, more and more children are living without adult supervision of any kind, often struggling to take care of younger brothers and sisters. Sometimes, children deliberately chose this option so they won't be separated from surviving brothers and sisters after their parents, aunts, uncles and older siblings die. These child headed households are growing in number and are especially vulnerable without support.

Children

Responses
- ✔ Becoming household heads
- ✔ Making household decisions
- ✔ Supporting younger siblings
- ✔ Participating on community orphan committees

Dangers
- ✔ Children have to leave school
- ✔ Girls are marrying earlier
- ✔ Children are entering the labor force earlier and are often exploited
- ✔ Children, especially young girls, are sexually exploited

Interventions
- ✔ Enable children to stay in school
- ✔ Reduce labor demands on families
- ✔ Psychosocial care
- ✔ Allow sibling adoption
- ✔ Income generation and job counseling
- ✔ Adequate child protection and community supervision

Despite their courage, children face many dangers, increasing as the epidemic worsens. Increased AIDS-related mortality has resulted in enormous demographic pressure on children and reduced protection through ordinary family and community mechanisms. This results in increased neglect, emotional and physical suffering, and increased exploitation of child labor and sexuality. Most often, orphans say that they miss the love of their parents and family. Many are traumatized permanently by the loss of care and protection in ways that are very similar to the damage experienced by children in war and other violence.

Key Determinants of Variation in Orphan Needs

- ✔ Age and sex of child
- ✔ Age of guardian
- ✔ Relationship of Guardian to Child
- ✔ Number of parents dead
- ✔ Proportion of children orphaned in the geographic area
- ✔ Inclusion/exclusion of orphaned children in family and community life
- ✔ Amount of AIDS-related stigma and discrimination
- ✔ Access to health education, and social services and safety nets

Interventions must be targeted directly to children in addition to families and communities, including those to enable children to stay in school or allow working children to attend alternative schooling. Children can be helped by interventions that reduce labor demands on families, but often also need their own income generation and vocational training. Children must be given access to State grants and supports directly before they are 18, and also be enabled, with appropriate supervision and limits, to adopt or foster their own siblings.

B. Families

Families in developing countries are anxious to do all they can to maintain their children in the home and village environment. In country after country of Sub Saharan Africa, families oppose the idea of orphanages because they remove children from the love and protection of their homes, from their property, village and traditions, and place them in an artificial environment that is not conducive for long term social development. Families are fostering children informally and formally, attempting to live up to their own and society's expectations, but as

pressure increases, find it more difficult to do so. These responses are similar in all of the countries that have conducted orphan assessments (Hunter, 1998 and 1999).

Families

Responses
- Adoption and fostering
- Changing member roles and responsibilities
- Expanding children's participation
- Working harder and more productively
- Balancing resources to meet growing needs

Dangers
- Burn out as more adults die or become ill
- Family resources not allocated to orphans
- Family labor demands intolerable
- Refuse to adopt or foster more children

Interventions
- Improve credit, jobs, income generation, infrastructure to reduce labor demand
- Protect women's property rights
- Provide women basic services and ensure access independent of men
- Psychosocial counseling

Studies in Malawi have shown that families need two things to continue care for children in spite of their poverty (Ali, 1998). The first is psychosocial help to deal with their own guilt, fear and grief and that of children who have lost their parents under very traumatic circumstances. The second is assistance to become more productive and innovative, so that fewer adult hands can support more children. Families are asking for simple things: fertilizer, improved seed and access to water so they can improve and ensure the productivity of their fields. They are asking for help in starting micro credit and micro enterprise programs so they can find a way to earn the income needed to feed and clothe children and send them to school (Ali, 1998; Hunter Malawi, Zambia and Zimbabwe, 1998).

Family willingness to help children remains undaunted if they can surmount the problems of making a sufficient living to do so (McKerrow and Verbeek, 1996; McKerrow, 1997). Financial allowances to foster families, such as are provided in developed countries, are being examined by governments as a way to assist families willing to take in orphaned and other vulnerable children. Financial support is usually non-existent, and social services – health, education, unemployment, social security – are often limited. In fact, most of the interventions needed by families are economic in nature, although psychosocial counseling helps families adjust to new members and additional burdens. Governments and donors need to consider the cost of not supporting families when they consider the long term cost of prevention and care programs. In the long run, family care is a much more cost effective and acceptable approach than institutional care of any kind.

Communities

Responses
- Child protection as community responsibility
- Orphan assistance committees
- Counseling and assisting guardians
- Programs by and for young people
- New channels of communication
- Fund raising and material support
- Voluntary vocational training
- Protecting widows' and orphans' property

Dangers
- Burn out as more adults die or become ill
- Resources don't match demand
- Labor demands grow intolerable
- Communities refuse to assist more children

Interventions
- Organizational ideas, training
- Limited material supports
- Recognition as official partners
- Assistance in accessing resources
- Psychosocial counseling
- Data collection and monitoring systems
- Development of service networks
- Openness about HIV/AIDS

C. Communities

Spontaneous family and community responses are the most effective, most affordable and least visible programs currently available to assist children and adults affected by HIV/AIDS. Arising in different countries and among people with different cultural traditions, they share many common elements. Communities enumerate children and vulnerable families, organize committees to plan assistance,

provide voluntary community services to the needy (day care, subsistence and commercial gardens, construction, shelter), and develop informal monitoring systems to ensure that children are not abused and guardians receive needed help. Even the poorest of communities make small donations to support their most destitute neighbors. This is especially true in communities that have been provided external support (McKerrow, 1997).

Communities where AIDS has taken a large toll view children as the responsibility of the village if individual families are too weak to provide effective care. Orphan committees intervene to assist guardians who were having difficulties caring for children, and provided counseling to harsh step or foster parents to help them adjust to the needs and demands of unwanted additional children. Community committees were more aware of children's needs and problems as a result of their new programs, and could articulate children's rights to protection. Community orphan committees provided children with forums to voice their problems and needs, and to receive counseling and guidance. In some countries, children and young people were participating on the orphan committees, contributing skills in record keeping, counseling, and planning. Young people in Anti-AIDS Clubs "adopted" vulnerable children, providing them material and emotional assistance (Hunter, Malawi 1998).

Communities see AIDS-related problems as problems in development, challenging them to work harder and more efficiently, to improve productivity and organization so that more children can be cared for by fewer adults (Hunter, Malawi/South Africa/Zambia/Zimbabwe 1998). Early childhood education is understood as a way to ensure the well being of small children efficiently (Hunter, Malawi 1998, Namibia/Swaziland, 1999). Pooled labor and technical inputs increase agricultural productivity (Hunter, Malawi/Zimbabwe 1998). Access to credit and microenterprise training can increase incomes through small business development. Voluntary vocational training passes on skills in tailoring, carpentry and other ventures. These changes have many positive development implications:

1. Community power structures are changing, leaving more room for the participation of women and young people;
2. Communities are seeking organizational innovations useful to other programs;
3. Civil society becomes more open and stronger as communities are trained in self-governance and mutual assistance through these programs;
4. Provision of material and organizational support can sustain community responses;
5. Changes in the community increase members' acceptance and uptake of development programs and inputs in agriculture, education, health and other areas;
6. As a consequence, the productivity of available labor was increased.

However, innovations are difficult to sustain as more children are orphaned, the burden of care increases, and there is little access to resources and support, like a bicycle for a volunteer traveling a wide radius to look in on AIDS patients or vulnerable children, or a length of garden hose to make watering communal gardens less time consuming. Small items can make a big difference in the success of community based programs over the long term. Communities also benefit from organizational support in a variety of forms:

1. Training in care giving, community organization, and income generating activities increases the quality of services provided to children and the overall skill levels of the communities where they reside;

2. Increased resources for income generating activities and other communal projects can stimulate greater participation and benefit and also ensure their sustainability;
3. Inclusion in formal social welfare systems for monitoring and referral will improve the quality of these services and help to see that children and families in need of specialized support will not "fall through the cracks";
4. Improvements in water and sanitation reduce labor demands on affected families and on community members who want to help;
5. Expanded provision of health and education services can increase access for orphans and their families and make sure these services are provided equitably to orphaned children;
6. Membership in service delivery networks can provide communities with moral and material inputs, recognition and systematic monitoring.

Many program and policy actions are needed to ensure communities sustain the burden, including:

1. Income support to poor households with persons living with HIV/AIDS or orphans. While this is legally provided in many of countries, budgetary constraints mean that few actually receive benefits;
2. Increased funding to public assistance programs would see that this is possible;
3. Tax credits to individuals, households and businesses that provide care would also stimulate a broader response;
4. Laws protecting the property of widows and orphans and promoting the writing of wills;
5. Payment to semi-professional care givers and community workers as part of the formal social welfare system so that their contributions are acknowledged and rewarded;
6. Engaging men more directly at all levels in finding solutions and sharing responsibility for care and prevention is critical both to stem the spread of HIV and in the development of equitable systems of care;
7. Families and children affected by HIV/AIDS are still suffering from considerable levels of discrimination, even in heavily affected countries, particularly if government and other officials do not acknowledge the epidemic.

D. Governments

Over the past decade, many governments in Sub Saharan Africa have been responding creatively and energetically to assist children, families and communities affected by HIV/AIDS. Countries have revised a variety of laws and created new policies to protect children. Judicial systems have been more flexible for women and children defending their inheritance and rights to property. Land tenure systems and property ownership have been opened up to women in several countries (Mozambique, Namibia, Tanzania). Uganda provides voluntary child advocates to help children redress exploitation. Zimbabwe, Malawi, and Zambia support village committees to assist children. Most governments are reviewing assistance programs so children without guardians are able to access support directly. Botswana, Namibia, South Africa, and Zambia, among others, provide for public welfare assistance and support to adopting and foster families but they are under-funded. In Zambia, for example, only 2% of the needy who qualify for support receive assistance (Hunter, Zambia 1998). A WHO study of home care patients in Botswana, entitled to

government disability, found that they couldn't afford food (Hunter, Botswana 1998). Health services may provide a way to monitor the status of vulnerable children, as may early childhood education centers, particularly those for the very young.

Government safety nets include:

1. **Adoption and fostering stipends** provided to families caring for children up to the age of maturity, 18 in most Eastern and Southern African countries;

2. **Public welfare assistance grants** provided to needy and vulnerable families, including those caring for AIDS patients, single mothers, disabled persons, and the elderly;

3. **Services through health, education and social welfare systems**, including primary care for mothers, children and for persons with infectious diseases; free schooling for all children or for orphans; and stipends and material assistance through social welfare for needy children and families.

Specific provision of the laws and the reality of the distribution of their benefits need to be analyzed. In South Africa, the Women's and Children's Budget Initiatives found that while the law provide many benefits to women and children, in actuality, they were limited by budgetary and administrative constraints (Institute for Democracy in South Africa, 1996). In Botswana, female headed households (47% of the total) form the majority of households living in poverty. These households are also more likely to be taking care of AIDS infected adults and their children (Botswana National AIDS Control Programme, 1996).

Governments

Responses
- ✔ National orphan policies
- ✔ Law review and codification
- ✔ Expanded social services
- ✔ Public assistance and support
- ✔ Tighter sexual abuse laws
- ✔ Modernize adoption and fostering laws and support
- ✔ Educating the public to protect families and children

Dangers
- ✔ Denying the severity of the problem
- ✔ Viewing orphans as a special case
- ✔ Not mainstreaming assistance through health, education and social welfare sectors
- ✔ Not protecting women's rights
- ✔ Not taking development implications seriously

Interventions
- ✔ Education about HIV/AIDS and social changes
- ✔ Advocacy for social service support
- ✔ Donor assistance to community and family support
- ✔ Knowledge of approaches in other countries
- ✔ Technical planning assistance

Economists, using limited models, suggest that HIV/AIDS will have little macroeconomic impact because many of the ill and dying are less skilled and educated, poor, and unemployed. These analyses suggest AIDS will reduce GDP growth by .5% per year, but they do not include costs of subsistence, provision of assistance for the sick, or long term care for orphans (World Bank, 1997). Models are needed that include the destruction of families, communities and social institutions, causing unimaginable human suffering and hardship in the future. The high stakes, in terms of loss of human potential, must be emphasized so that more resources are drawn into government efforts to control the epidemic and provide care for those it leaves vulnerable. In Sub Saharan Africa, even the most enlightened governments are working with diminishing resources to assist children, families and communities affected by HIV/AIDS. Donor resources, focussed on prevention, are only now being provided to programs of care.

Private Sector Initiative -- Zimbabwe's Farm Orphan Support Trust

The Farm Orphan Support Trust (FOST) is a state registered national program which solicits and facilitates support for children in especially difficult circumstances, particularly orphans, on commercial farms. The aim is to proactively increase the capacity of the farming community to respond to, and care for the most vulnerable individuals, in the emerging orphan crisis. Government resources are inadequate to cope with the magnitude of the problem and children's institutes are already overwhelmed.

Two million people, 17% of the total population, live on commercial farms. Farm workers are multi-ethnic and families are often isolated from their extended family networks, which traditionally involve relationships of obligation and responsibility.

Agriculture is the most important productive sector in Zimbabwe's economy and commercial farming is the largest single employer of labour The Commercial Farmers' Union (CFU) is an umbrella organization representing large-scale agricultural producers. The CFU has had an active HIV/AIDS prevention program since 1986. In 1996, following initial research, situation analysis and a national seminar, FOST was formally launched with government approval and CFU logistic support.

The Executive Committee of FOST has representation from farmers, both employer and employee Unions, Government, the University, Churches and NGOs. The committee may co-opt expertise where needed. The CFU also provides access to farmers and farm workers through its national structures.

FOST aims to keep sibling orphans together, within a family of the same culture, and in a familiar environment. Foster care schemes development on farms involves using existing structures, such as farm development committees to: identify the need; create community awareness and select Child Care Committees; train caregivers; establish monitoring channels; promote "community projects" and disseminate information. Farms individually register orphans and send duplicate details for computerized data banking. This assists in relative tracing, advocacy and forward planning.

The program promotes five levels of care, in descending order of preference:
1.Within the extended family. 2.Placement in substitute families. 3.Small groups of orphans, living together, overseen by a carefully selected caregiver, employed by the farmer for that purpose. 4.Adolescent Child-Headed Households with siblings remaining together, preferably in the family home, cared for by the eldest child, under the regular supervision and support of the Child Care Committee, the community and the Field Officer. 5. Orphanages, as a temporary place of care until an alternative solution can be found, particularly for babies and very young children.

Key to sustainability is not only community acceptance of the responsibility for orphans, but also adequate support, provided by the combined efforts of the community, farmer, Government and society in general. Farm level of support, such as the provision of accommodation, seed and land for cultivation, income generating projects, and women's club self-help initiatives, is determined both by community motivation and by the farm viability. FOST is exploring innovative forms of funding from Industry and Commerce as well as Government support for free education and health care for orphans, and tax credits for those involved in the scheme. The aim is not to only benefit the orphans, which may result in reverse discrimination, but to uplift the entire community.

E. PrivateSector

Private commercial farms in Zambia and Zimbabwe have provided support to Persons Living with HIV/AIDS and to their dependents in a variety of innovative ways (Parry, 1999; Hunter, Zimbabwe 1998). While commercial farmers are popularly villanized and used as political scapegoats in some countries -- and some do exploit poorly regulated employment situations -- most are competent business people who recognized the effect of the epidemic on their labor force. In some cases, farmers have acted in the best interests of their employees against a government that is actively discriminating against farm employees as a way to reduce their legal responsibility. Tanzanian employers and those in neighboring countries have long been involved in AIDS prevention activities ranging from the distribution of condoms to provision of regular screening and treatment for STDs. Unions act as a power force in many countries to raise sick pay and benefits for survivors. In Botswana, the private sector, through the Rotary Club, is assisting communities with development of microcredit and microenterprise projects. Rotary

International has considered fund raising for orphans when their current campaign for polio is terminated.

VIII. Going to Scale

A. Short and Long Term Programming

In the short term, a national orphan program requires investment in a planning and monitoring system, maintained to coordinate and guide program implementation. In the long term, implementing agencies should integrate family and community support programs into health, education, agriculture, water and sanitation sectors, key in determining family and child well being.

Type of Care	Proportion of Vulnerable Children	Complexity	Experience	Cost Per Child
Institution	**5%**	**Low – Independent Operations**	**High**	**High**
Temporary	**5%**	**Low – Independent Operations**	**High**	**Medium to High**
Family	**55 – 65%**	**National System Development** **Family Behavior Change**	**High**	**Low**
Community	**25 – 35%**	**National System Development** **Community Behavior Change** **Local Systems Development**	**Low Precedents in Some Countries**	**Low**

A national implementation strategy needs to recognize that in the short term (3-5 years), a national orphan program requires investment in program-specific services to:

1. Organize national, regional and local coordinating committees;
2. Catalyze community organization and build community capacity for care;
3. Develop networks of service providers;
4. Undertake legal review and policy changes;
5. Develop data collection, modeling and research capabilities;
6. Establish a monitoring and evaluation system;
7. Develop public and policy maker awareness;
8. Undertake fund raising for expanded programming.

Programming needs to be vertical and focussed until the ground work for long term responses is laid. It may take 5 years or longer to pass through the initial organising stage because of

decentralization and multisectoral involvement. Even then, a country may wish to maintain a national body for advocacy, on-going monitoring, and policy and program development.

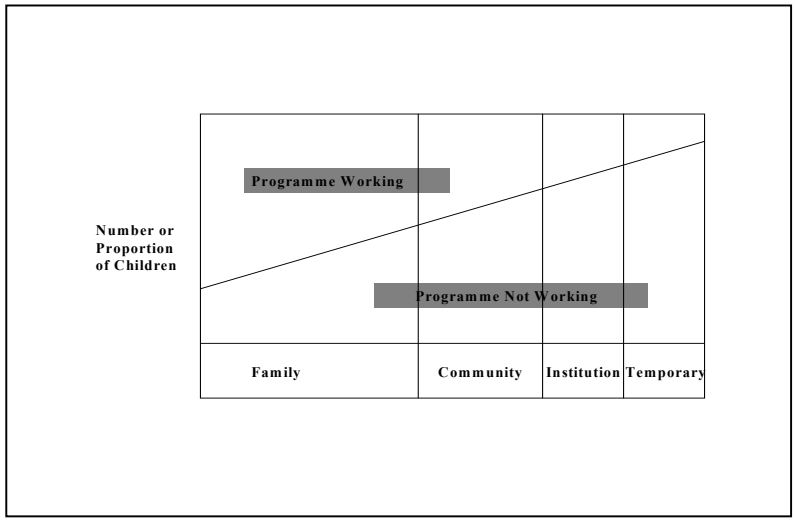
The first step in mainstreaming is to review how effectively programming in all sectors responds to the needs of orphaned children or other children left vulnerable by the epidemic. In countries where orphans are a significant minority of children, this will be especially critical. Over the long term (5-10 years), implementing agencies can integrate family and community support programs into mainstream programs in health, education, agriculture, water and sanitation, key sectors determining a country's progress in meeting the goals for children and families.

B. Monitoring and Evaluation

Once a national strategy is developed, the monitoring and evaluation plan can be developed using strategic goals and objectives. There are several broad areas for monitoring and evaluation:

1. **Coverage of vulnerable populations** by geographic area and by sources of vulnerability. This includes child health and well being, care giver status, and community status and changes over time. While there are indicators for the first two areas, little work has been done in the third;
2. **Performance of service providers**, including the performance of organizations as well as their viability and sustainability over time given a range of resource constraints;
3. **Outcomes or impact of programs**, for which baseline data will be needed. Indicators can be developed by category or vulnerability of children, and it will be needed to measure impact on care givers as well as on children.

Process indicators measure the implementation of programs in terms of outputs (numbers of children served, services provided). These are needed in the early stages of program development to measure the progress of program implementation, and the functioning and sustainability of community organizations. Impact or outcome indicators measure the success of programs by their ability to support family and community survival and maintenance of child well being and health. These are essential to long term program planning, and are needed to attract donor funding and private sector support.



A monitoring and evaluation plan for orphan programs will be similar to those for other child protection, health, or education programs. In fact, basic indicators for child well being may be same as those used in other programs, but survey instruments should compare their values for orphans and non-orphans, or for children in foster homes versus children in parental care. It may

be useful to evaluate maternal and paternal orphans separately because their problems will be different at different ages. This type of evaluation has been conducted in small scale studies (Hunter, 1990; Foster, 1993), in area studies (World Bank, 1997), and values have been compared nationally using DHS data (World Bank, 1997). Given the large portion of children orpahned, these comparisons must be instituted as a routine part of periodic national studies. .

Deterioration of all children's well being may be seen because of the pressure on families and communities of more dependent children. In several heavily affected countries, the possibility of emergency conditions is anticipated in the next few years. For this reason, a monitoring plan should include:

1. The overall situation of children and their care givers, established using regular national sample surveys. Poverty alleviation or DHS surveys might be ideal for this purpose;
2. Monitoring of performance of specific projects, especially pilot projects prior to widespread implementation.

Growth in vulnerable children's populations, such as street children, working children, or child headed households is an indicator of the saturation of community coping (Ahmed et al., 1999). Criteria for prioritizing vulnerability of children and families within communities are needed by poverty level and by vulnerability of household or guardian. These can be established by the community itself according to its capacity for assistance (see, for example, Hunter's Malawi, Zambia and Zimbabwe reports). In addition, program planners may wish to prioritize among communities needing assistance for purposes of targeting vulnerable communities and targeting entire regions or areas (Mozambique, Namibia,Tanzania, Kenya).

C. Research and Training

Research needs are many. First, most countries needed to consciously link in-country research capacity with on going implementation so that simplified operations research, conducted by communities, can inform implementation and help policy makers better understand needs (Ali, 1998). Where there is sophisticated demographic research capacity, it needed to be focussed on the issue of orphans and other changes in demographic structure due to AIDS (Mukiza-Gapere and Ntozi, 1995).

Models for evaluating community response over time, as the epidemic increases mortality, are needed so that support to communities can be adjusted over time. Again, these can be developed using simplified data collection instruments for the community to monitor and adjust its own response. Models are also needed to guide implementation in different settings: urban, rural, and commercial locations. These are being evaluated in Zimbabwe and South Africa. The issue of "grand orphans", or second generation orphans needs to be studied to determine its extent over time. Child headed households are also especially vulnerable. Child and community vulnerability indices are needed so that fragile situations can be identified early and addressed. Finally, all community care issues need research and analysis, including community care as women's work and the impact of care on women, as well as increasing the involvement of men.

These are simple research problems that can make use of community data. Many projects are training community committees to select their own indicators and collect their own data for

monitoring and evaluation. In Zambia, communities ae designing and implementing their own Community Based Information Management Systems. Similar systems were developed in Tanzania (Community Management Information Systems). The approach democratizes evaluation and management and ensures community leadership in program change.

Training needs are also many at all levels, including care givers, communities, social welfare officers, and for university faculty in many disciplines. Training is needed for volunteer and organizational staff so programs can be expanded rapidly.

D. Program Quality and Development

A monitoring and evaluation plan can look at the quality of programs in place to serve children, families and communities affected by HIV/AIDS. Are they sufficiently comprehensive? What other models could be encouraged, and how can models be expanded to meet new needs or provide new services?

Is there periodic training for community committees and for family care givers? What allowances are made for development of programming over time in response to changes in the epidemic? What are the material needs and supports? How do programs encourage innovation, including opportunities for communities to teach and talk with one another? What variation is there in response to differences in program setting (urban, periurban, rural, commercial and farming settings)? How are children's physical needs, needs for socialization, and psychosocial needs met?

Program development seeks to encourage change and innovation in program approaches that respond to changes in communities as AIDS mortality increases. Communities will need assistance to ensure the sustainability of their programs, including:

1. Working structures and networks;
2. Skills training;
3. Ownership of programs;
4. Awareness of program impact;
5. Close cooperation of government and NGOs with community based organizations.

E. Fund Raising

A funding plan can include indigenous sources of support as well as external. Indigenous sources of support include the government, communities, religious organizations, commercial or private sector organizations, community fund raising, and small contributors of cash and in-kind goods and services. External sources of support included program specific support from UN or multilateral donors, non-governmental organizations, bilateral donors, external funding to religious organizations or hospitals, and World Bank AIDS sector loans.

Collaborative support and synergistic potential can be gained through coordination with donors supporting primary education, health programs, and agricultural programs. Orphan programs also built on programs developed in other sectors. Villagers in Malawi who had participated in a UNDP community development program were quicker to organise around the orphan issue in subsequent years. Programs in other sectors could be targeted at communities with large numbers of orphans. For example, a high protein seed program organized by the World Food Program was targeted at heavily affected communities with good results.

National, district and local coordinating committees often stimulated local interest and contributions. In-kind contributions of good and services were often as important as cash contributions and may be easier for groups or individuals to provide. Expanded funding in other sectors by donors can be used to support mainstreamed services for orphans. For example, programs for early childhood education and development are especially important in supporting young orphans. A national development plan and strategy for orphans will be important in increasing funds from external donors and programs because it can articulate the scale of the problem, strategies being pursued to address it, and the contributions being made by local communities and organizations.

IX. Special Issues in Need of Further Study

A. Community Care and Women's Rights

Lack of respect, protection and fulfillment of women's rights has long term impacts on the effectiveness of both prevention and care programs for HIV/AIDS. Many women and girls who are HIV positive in Sub-Saharan Africa and Asia contracted the virus involuntarily due to the extramarital sexual activities of their male partner. Once positive, these women cannot protect their property from theft or their children from exploitation. In many countries, changes in family structures over the past several decades in response to global and local economic and social conditions (Bruce et al., 1997; Institute for Democracy in South Africa, 1996) have not benefited women or supported family care:

1. **Families and households are smaller**. During the 1970s and 1980s, the average household size fell almost 10% due to declining fertility rates, household dispersion for employment, separation, famine, disease, and war. Family support networks are getting smaller, resulting in reduced financial security and fewer alternatives for child care;

2. **More women are in the labor force**. Women's participation in the labor market is

Women and Poverty in Botswana

"Although Botswana has one of the leading macro economic and social indicators in the African region, poverty remains a major problem. The income gap between the poorest and richest members of society in Botswana is high. The poorest 40% of the population get only 11.6% while the richest 20% get 59% of the income. The most recent available data show that 47% of the population live in poverty, 62% of these are in the rural areas while 38% are in the urban areas. Female headed households form the majority of households living in poverty. The 1991 census data show that 47% of the households in Botswana are female headed and 52% of these are in rural areas. This level of poverty is likely to make most people, especially women and those in the rural areas vulnerable to HIV infection and less able to respond effectively to its consequences. Issues of literacy, unemployment and gender are predisposing to HIV infection in Botswana."

Medium Term AIDS Plan II, 1996

increasing while men's is declining, but laws and traditions are not changing fast enough to assist women who must assume additional economic responsibilities without reduction in household responsibilities or supportive social and legal changes. Privatization of education and health are especially problematic for women, who work longer hours than men and often not for cash.

Some 75% of the world's women live in countries where the per capita gross domestic product is either declining or stagnant. Women are the sole earners in more than a quarter of the world's households and these households are disproportionately poor. In many African countries, women are perpetual minors. They cannot own or inherit land and property, and they cannot enter the labor force without their husband's permission;

3. **Marriages are later and less stable**. During the 1970s and 1980s, the proportion of never married women ages 20 to 24 rose in countries in all world regions. In many areas, this has resulted in delayed childbearing, although adolescent pregnancy remains high in Sub-Saharan Africa. Women are waiting longer before their first marriage and childbirth, in part because opportunities for work outside the home have grown. In addition, women's marital status varies markedly throughout life due to divorce, separation and widowhood. Polygamous, serial, and multiple marriages are becoming more common, reducing male support for offspring and increasing women's uncertainty. Between 40 and 60% of women surveyed by in Sub-Saharan Africa, the Middle East and Asia indicate that their first marriage has dissolved due to death of their spouse or divorce, as did 25% or more in other regions. From the child's perspective, these relationships create more siblings and hence more competition for scarce resources.

4. **More households are supported by single women**. More children are being raised by one parent, usually their mother, due to high and increasing levels of martial dissolution, increased non-marital childbearing, labor migration, and polygamy or competing sexual relations. With the AIDS epidemic, more women are losing their husbands or partners at earlier ages. The proportion of female headed households is increasing – ranging from 15.6% in Cote d'Ivoire to 49.7% in Botswana, and more generally running from 20 to 30% in Sub Saharan Africa – and women are assuming greater responsibility within families due to increased rates of divorce. More than 20% of never-married women in seven Sub-Saharan African countries surveyed by DHS and 10% in three Latin American countries have given birth. In Ghana, 50% of a woman=s reproductive years are spent living without a resident partner. In Kenya the figure is 43%, in Mali 20% in Senegal, 33%. Only a small proportion of these (less than 10% to half) are designated as household heads.

5. **More children depending on female incomes**. One-quarter of married women in Asia and North Africa and one-third in Sub-Saharan Africa, Latin America and the Caribbean will experience the death or husband or divorce by the time they are 45. Loss of the man jeopardizes the woman's access to support for her children, from labor market, the extended family, and the State. Many children have mothers with attenuated access to the resources of other family members because they are household heads, in polygamous marriages, not formally married, or their husbands

are migrants. Children may be more vulnerable because their mothers have lower literacy and are younger. In all but a few countries, more than two-thirds of children have mothers who do not currently work for cash, but when they do they put more time into income generating work than men because their wages are lower and they contribute proportionately more of their income to the family when they do earn it.

Although female headed households tend to be poorer, children sometimes fare better because more of the income is used for their benefit; Although census, economic -- and even AIDS-related data collection -- has tended to obscure the importance of women's economic contribution to families, evidence is accumulating that women's support is critical to the well being of children and that the proportion of female supported households is high and growing.

6. **Male Attachment**. Men's attachment to children is generally mediated by a woman. In only 2% of societies do men have regular and close relationships with infants and in 5% with young children. Fathers contribute one-third as much time as mothers to direct child care (less according to mothers' estimates). With few exceptions, fathers bond mostly with their older, male children.

Advocating community care for children orphaned and left vulnerable by the epidemic may have unanticipated negative consequences for women, unless other gender inequities are addressed. In South Africa, community care for orphans was viewed as additional unpaid women's work, and the long range justice of community care is questioned. Female orphans are removed from school sooner than boys to provide sick and child care and other domestic work. Women who are providing care are unable to seek other kinds of employment, and the value of their labor goes unrecognized. Worse still, as women loose education and employment opportunities, the gender inequality that initially fueled the spread of the AIDS epidemic is perpetuated into future generations. While in the past, development strategies have emphasized children's well being as a priority, failure to concertedly build and protect women's rights has left them completely vulnerable to the epidemic.

South Africa's *Women's Budget*, 1996

"Much of women's disadvantage is rooted in the sexual division of labour. Across all class, race and other groupings women generally bear a greater burden than men of the reproductive tasks such as childbearing, childrearing and domestic work. These tasks are usually unpaid…

"Reproductive work is essential to the functioning of the economy and to society….In essence, unpaid labour produces the social infrastructure which is as important, if not more so, than the physical infrastructure…At the same time women's burden in reproductive work limits the time, energy and opportunities which they themselves can devote to income earning…

"We therefore see the acknowledgement of unpaid labour as crucial to women's empowerment…women's unpaid domestic and childbearing work should be regarded as a tax they must pay before engaging in economic activity…These issue have even more pertinence in South Africa than in more developed countries. In South Africa it is not only conventional housework that is unpaid, but also the fetching of water and fuel, and the more "productive" subsistence agriculture performed by women and men in rural areas."

B. AIDS and the Rights of Poor Communities

Depending on the country and infection levels, an estimated 25 to 75% of all households are providing care to foster children (Hunter 1998 and 1999; McKerrow, 1995 and 1996; Serpell, 1997 and 1999; Webb, 1996). Of these, many are female headed households, which are the poorest. In many countries, statistics indicate that orphans are sent to rural areas following the death of parent or caregiver,

where households are generally poorer, older, experience more food shortages, and have less access to services, including health care, education, clean drinking water, sanitation, and public assistance of any kind. In Zambia, for example, 87% of rural households are classified as extremely poor, while 54% of urban households are in that category. More than 70% of households – over half of which are extremely poor -- include foster children. The majority report preferring to take care of children within the family, but many are afraid that they cannot because of economic limitations. An estimated 89% receive some kind of assistance, but only 14% from a formal government, NGO, or church program (Zambia, 1997).

Economic adjustment programs have weakened social services, health services, and public assistance schemes in all these countries, leading governments to abrogate responsibility for family welfare to local governments and community charity. Families and communities must respond in the best ways they can, and the coverage and effectiveness of their efforts are not being systematically monitored or evaluated. This leaves the most vulnerable – children, women, the elderly, the disabled -- exposed, with weak or nonexistent safety nets and no resources other than their own creativity. Communities are not assisted because it is feared that they will become dependent. At the same time, the concentration of wealth in most of these countries is increasing.

Community volunteers are expected to function as social welfare systems, in some cases with little or no organizational inputs. They need training, continued development, and hardware, such as bicycles, water pumps, and capital for revolving credit and income generating activities used to support poor children and sick community members. In Zimbabwe, the government acknowledges volunteer community committees as a formal part of their social welfare structure. Communities are being empowered by this to handle child protection issues on their own. Although Zimbabwe probably provides the highest coverage through such systems, spending by government agencies charged with their development is frustratingly slow.

It is important that development agencies anticipate what such volunteer systems need to sustain themselves, and treat them with sufficient respect to prepare for their perpetuation. No government or UN agency or NGO worker would ever be expected to work under the conditions and with the resource constraints that these volunteers face. To ensure sustainability of community based care and prevention programs:

1. Operational or action-oriented research is needed in selected countries with the guidance of skilled economists to elucidate the impact of community care models on women and female headed households;

2. The research also needs to investigate the "bottom line" of caring, the point at which households willing to provide care are unable to do so given restrictions of time, money, and other resources;

3. Recognition must be given to the fact that African family systems may not be able to sustain themselves under the burden of adoption and fostering not because they are unwilling, but because they are too impoverished;

4. The concept of community dependency be eliminated from development theory and strategy in response to the impact of AIDS. Communities are willing and resourceful, albeit

impoverished, partners. Communities may well be dependent because they experience abject poverty, because they are allocated too small a share of national wealth and other resources, such as education, health care, water, and sanitation, capital and credit. It is cynical to fail to reconceptualize our ultimate reliance on them for child welfare and act accordingly;

5. Communities be given proper acknowledgement as viable delivery mechanisms for a range of social services;

6. Appropriate support to sustain community development in these areas, including organizational training and material assistance, transportation and agriculture, is needed in all programming.

Hunter
November 1999

Footnotes

[1]Sections of each of these reports were co-authored by UNICEF country office staff who are acknowledged in the introductory section of each report. Considerable support was also provided by Deguene Fall, who traveled with Hunter on the first six assessments and developed documentation of the logistics of the visits.

[2]This chart and that on page 16 were developed in part during a workshop held at a meeting of UNICEF Child Protection Officers and counterparts from 15 countries in Nairobi in April, 1999.

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