

**CARE FOR ORPHANS, CHILDREN  
AFFECTED BY HIV/AIDS AND OTHER  
VULNERABLE CHILDREN**

**A STRATEGIC FRAMEWORK**



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FAMILY HEALTH INTERNATIONAL  
HIV/AIDS Prevention and Care Department  
2101 Wilson Boulevard, Suite 700  
Arlington, VA 22201

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<b>I.</b>	<b>INTRODUCTION</b>	<b>2</b>
<b>II.</b>	<b>STATE-OF-THE-ART: PROVIDING COMPREHENSIVE CARE AND SUPPORT FOR CHILDREN IN NEED</b>	<b>3</b>
	Policy and law	
	Medical care	
	Socioeconomic support	
	Psychosocial support	
	Education	
	Human rights	
<b>III.</b>	<b>FHI GOALS AND OBJECTIVES</b>	<b>6</b>
<b>IV.</b>	<b>FHI's TECHNICAL AND PROGRAMMATIC APPROACHES</b>	<b>7</b>
	Guiding principles	
	FHI's approaches	
	Emphasizing community care rather than institutional care	
	Strengthening the care and coping capacities of families and communities	
	Involving children and youth as part of the solution, not part of the problem	
	Building broad collaboration among key stakeholders in all sectors	
	Application of long term perspective	
	Integration with other services	
	Linking care and prevention	
<b>V.</b>	<b>ILLUSTRATIVE ACTIVITIES</b>	<b>11</b>
	The Zambia Strengthening Community Partnerships for the Empowerments of OVC (SCOPE) Project	
	Siyawela OVC Project of Hope Worldwide, Soweto, South Africa	
	Nyemo II Counseling Centre, Cambodia	
<b>VI.</b>	<b>INTERVENTION-LINKED RESEARCH</b>	<b>13</b>
<b>VII.</b>	<b>MONITORING AND EVALUATION</b>	<b>13</b>
<b>VIII.</b>	<b>LINKAGES AND PARTNERSHIPS</b>	<b>15</b>
<b>IX.</b>	<b>FURTHER READING</b>	<b>16</b>

## I. INTRODUCTION

The global HIV/AIDS pandemic has been changing human lives and the shape of societies for more than 15 years in the heavily infected countries of Sub-Saharan Africa, Asia, Latin America and the Caribbean. It has reversed decades of development gains in health, and slowed economic and social improvement across the board and in ways that will change relationships at family, community and national levels forever.

One measure of the massive social change still to come is the number of orphans, children affected by HIV/AIDS, and other children made vulnerable by the pandemic. According to revised 2000 estimates, there are currently 34.7 million children under age 15 in 34 countries who have lost their mother, father, or both of their parents to HIV/AIDS and other causes of death. By 2010, that number will be 44 million. Without AIDS, the total number of children orphaned would have declined by 2010 to less than 15 million. In 2010, 20 percent to 30 percent of all children under 15 will be orphaned in 11 Sub-Saharan African countries, even if all new infections are prevented and some form of treatment is provided to slow the onset of AIDS in those infected with HIV (*Children on the Brink 2000*).

The human and social costs these estimates represent are staggering. Although the overwhelming majority of orphans and vulnerable children are living with surviving parents or extended family, many of them are being cared for by a remaining parent who is sick or dying, elderly grandparents who themselves are often in need of care and support, or impoverished relatives struggling to meet the needs of their own children. Children living in these situations are at increased risk of losing opportunities for school, health care, growth, development, nutrition, and shelter; in short, their rights to a decent and fulfilling human existence. Moreover, with the death of a parent, children experience profound loss and a heavy burden falls to the surviving parent. If the second parent also dies, all aspects of that child's world are threatened. Studies in many countries find that families and communities will absorb orphaned and affected children as long as their resources are sufficient. When the family and community capacity to absorb children has been reached, increasing numbers of children must look after themselves. Often the eldest child takes responsibility as the head of the household. Some of these children are left with no other option than to live on the streets, exposing them to even greater medical, social, and psychological difficulties.

The growing demand for care and support of orphans and vulnerable children at the community level has strained traditional coping mechanisms to a crisis stage in the most heavily affected countries. An increasing number of communities and government structures are struggling to harness the impact of AIDS on children and their families. In the absence of support there will be long-term developmental impacts on children and the future of these countries. Failure to support children to overcome this trauma will have a very negative impact on society and might cause dysfunctional societies, jeopardizing years of investment in national development.

Care and support for orphans and vulnerable children has primarily focused on addressing their material needs. The secondary focus of programs has been to address the needs for skill transfer and education for children. Even fewer programs have been able to adequately address the medical, social welfare and psychological needs of children affected by AIDS. It is essential that medical care, socioeconomic support, human rights and legal support, and psychosocial support interventions are implemented in the mutually reinforcing manner necessary to provide comprehensive care and support for orphans and other vulnerable children. Although programs have responded to some of these needs and elements, they are often fragmented and lack a comprehensive approach. It is widely

recognized that one organization or program cannot address all of these needs alone. Yet, partnerships are still few and programs to date have had extreme difficulties in adequately reaching the number of children in need.

Although African and Asian countries have responded with comprehensive policies and plans of action for these children (Malawi, Zimbabwe, Thailand), most countries have national plans still in development. At the community level, various community groups have developed a wide range of responses. The extent of these responses is not known, but there is general agreement that geographic and programmatic coverage of existing programs is insufficient.

The challenges faced by children, families, communities, and their governments in managing the impact of HIV/AIDS are and will continue to be enormous. Therefore, comprehensive and cost-effective approaches, coupled with coordinated partnerships and community mobilization, are needed. It is also imperative to replicate, scale-up, and sustain these approaches to meet the short- and long-term care and support needs of orphans and other vulnerable children.

This document provides a strategic framework to assist national and local planners, implementers, and donors in setting priorities, and outlines the steps necessary to develop responsive care and support programs for orphans, children affected by AIDS and other vulnerable children. It also elaborates on the role that FHI can play in this effort.

## **II. STATE-OF-THE-ART: PROVIDING COMPREHENSIVE CARE AND SUPPORT FOR CHILDREN IN NEED**

The impact of HIV on children and their families is not a simple problem with a simple solution or quick fix. There is no recipe or road map, although there is growing consensus about the broad outlines of a strategic response, as reflected in *Children on the Brink 2000* and the evolving set of principles to guide programming for orphans and vulnerable children (see below). The reality of the current situation is complex, inter-related on all levels of life, and cuts across all sectors of development. This is not a matter of children alone but one of all individuals, societies, and governing bodies locally, nationally, and internationally. We are faced with a situation of an unprecedented nature that requires the trust and respect of communities, collaboration and commitment at all levels, and the sharing of lessons learned.

Yet, there are state of the art elements for the care and support of orphans and other vulnerable children (OVC), that stem from lessons learned in various countries and experiences from programs including development, child survival, children of war, and other HIV/AIDS-related programs. These elements are interrelated, mutually reinforcing and require the involvement of all levels of society. This section describes the elements of a comprehensive care and support program that, when given equal attention through partnerships, responds to the various needs of orphans and other vulnerable children.

- **Policy and law** – Appropriate government policies are essential for the protection and well being of orphans and other vulnerable children and their families. These policies must contain clauses to prohibit discrimination of access to medical services, education, employment, housing, and protect the inheritance rights of widows and orphans. While most countries have child welfare laws, their application for the protection of street children and other vulnerable children needs to be strengthened. Policy options include ensuring access to

education and basic health services; protecting inheritance rights of widows and orphans; preventing inappropriate institutionalization; ensuring the provision of better alternative forms of care for children without adequate family care (foster care, adoption, small group homes integrated in communities); ensuring existing residential care meets children's developmental, psychosocial, and material needs; Protecting street children from abuse; protecting children from abuse and neglect; protecting children from sexual abuse or exploitation; preventing harmful child labor practices; improving access to limited resources (land, labor, capital, draft animals, management skills); promoting optimal resources use (improved technologies to improve productivity, economic support, income generating activities); empowering affected groups (child-headed households, widows, grandparents, orphans, youths) by developing their ability to support themselves. Formulation and revision of these policies and laws should fully consider the challenges that are faced by people living with HIV/AIDS, children and families affected by it, the potential for government action to have a significant impact, and be in line with the Convention on the Rights of the Child.

Some countries, such as Malawi, have established a policy framework specifically to protect orphans, guide the way services are provided for them and define respective government and NGO areas of responsibility.<sup>1</sup> Other countries, including Uganda, Thailand and Senegal, have shown that open, committed leadership and political will can make a difference.

- **Medical care** – For the maximum well-being of orphans and other vulnerable children to be reached they and their guardians need to have access to appropriate health care including clinical and preventive health care services, nutritional support, palliative care and complimentary home-based care, and full and relevant information. In the case of unknown HIV status of children born from HIV infected mothers, nutritional and infant feeding support is essential and, whenever the HIV status of the child is known to be positive, preventive therapy against common opportunistic infections is recommended as the standard of care. The implementation of ARV regimens to improve and extend the lives of children infected with HIV is to be considered whenever accessible and feasible. Yet, this is still a neglected area due to their high cost and the complexity of implementing systems to adequately implement this service. Nevertheless, concerted efforts to make ARV therapy available for children still need to be explored and strengthened. The capacity of programs for children living with AIDS to provide or link up with adequate medical attention needs to be stressed. Even where ARV therapy may not be possible, better access to treatment of opportunistic infections could help prolong lives, both for children with HIV and parents with HIV. The roles family carers and guardians can play if fully informed about preventing and caring for medical conditions is still underestimated.

It is also important that parents and guardians have access to appropriate preventive and curative medical care including access to ARV regimens for those who are infected with HIV. By improving and extending the lives of parents and guardians, orphanhood will be postponed and other interventions to prepare the child for a transition can be implemented to prevent the long-term problems orphans face.

- **Socioeconomic support**– Orphans and other vulnerable children and their families are confronted with severe threats to their well-being including isolation, loss of income, educational access, shelter, nutrition and other essential necessities. When families and children are forced to focus on daily basic needs to decrease their suffering, attention is diverted from factors that contribute to long-term health and well-being. It is widely

recognized that most of the problems faced by AIDS-affected children and households result either directly or indirectly from the economic impact of AIDS.

To mitigate the socioeconomic impact of AIDS, communities must be able to identify children and households most in need, prioritize their needs, and use local and external resources to increase their well-being and strengthen community safety nets. There should also be special attention to child-headed households, families with young children headed by the elderly; families with young children headed by adolescents and abandoned newborns. Outreach programs in cooperation with social welfare can also provide human resources and technical assistance to households identified as taking care of orphans, headed by children and adolescents.

Increased community mobilization and capacity building and partnership between communities and key stakeholders including government agencies, religious organizations, community leaders, NGOs and other community groups is crucial in the response to socioeconomic needs of orphans, other vulnerable children and their families. State-of-the-art microfinance programs have shown good potential for increasing economic resilience among poor households in a sustainable, cost-effective manner. Village banking is perhaps the best known of such programs. One of the critical elements in the use of these types of interventions is that they are provided by established microfinance organizations and geographically overlap with programs for orphans and other vulnerable children rather than specifically targeting beneficiaries of HIV or OVC projects. Microfinance experts and research shows that this will strengthen community safety nets.

- **Psychosocial support** – The psychosocial needs of children continue to be one of the most neglected areas of support. The HIV epidemic has increased the urgency to address psychological problems of children in an equal proportion to other interventions. Children are affected by the changes in their parent's emotional and physical state. They may not know what is happening to the parent and become confused and frightened. When a parent becomes terminally ill, older siblings are often forced to take on a premature parenting role for their younger siblings and nursing care for their parents. Without proper support mechanisms upon the death of a parent children experience a profound sense of loss, grief, hopelessness, fear and anxiety. Long-term consequences can include psychosomatic disorders, chronic depression, low self-esteem, low levels of life skills, learning disabilities, and disturbed social behaviour.

Before a parent dies it is essential that the parent have access to psychosocial support. Programs have begun to effectively establish support groups for infected adults whereby they can discuss and gain support for their own needs. The memory box (e.g., containing photos, identification books, diary or letters etc) is a simple tool that can assist parents to recount the family, cultural history, and memories of children's childhood activities. The development of memory books is also structured so that it leads, in a comfortable way, into possible will writing and disclosure.

Before a parent dies it is essential to deal constructively with plans for their children's future and the children's fears about how and with whom they will live and how they will stay in school. When a parent discloses to a child, if there is no remaining parent, ideally an extended family member should be identified who can become the guardian of the child. Upon disclosure the child should be told the plan. This can help ease the psychological burdens of both the parent and child. Keeping siblings together also provides them an important sense of continuity and is a source of support and identity. Religious and traditional practices for dealing with grief and mourning permit the expression and release of intense emotions.

Finally, ensuring ongoing care and support for orphans is critically important to their well-being. HIV-related programs need to include components for children and link with other child focus programs. It is essential to incorporate effective measures into other activities and include: helping extended families and communities provide consistent support for children, training teachers to recognize and respond supportively to withdrawn or disruptive behaviour or a drop in academic performance, and supporting communities to conduct structured recreation, art, cultural, and sports activities that enable isolated orphans and other vulnerable children to socially integrate.

- **Education** – Education plays a vital role in the well being of children. It not only offers them a chance for their future but also provides developmental stimuli. The impact of HIV on the educational system has resulted in a decreasing number of teachers due to mortality, a growing number of children who are not able to attend or stay in school, and rising numbers of pupils whose ability to take advantage of schooling is undermined by other factors including poor nutrition, psychological stress etc. The quality of education is also at risk of declining due to teacher shortages related to illness, and teachers' having to care for sick relatives, or attend funerals.

Each of the above areas of concern needs to be addressed to increase the access and quality of education for children. Different interventions to do so include accelerating actions to ensure that universal primary education is available to all children regardless of their social situation, community schools, incentives to schools to allow the most needy children access to education, and educating staff and students about HIV/AIDS including discussions about how children are affected and students can support each other. Educational activities need to be linked to other interventions, such as nutrition and psychosocial, to have a holistic program that addresses influencing factors on children's ability to attend school and maximize the benefits of education.

- **Human Rights** - Human rights-based approaches have been increasingly recognized as essential to the success of HIV prevention and care programs, including those working with children and adolescents. Governments have committed themselves to respecting, protecting, and fulfilling human rights by ratifying human rights treaties, such as the Convention on the Rights of the Child. Additionally, many NGOs utilize human rights as a programming framework.

### III. FHI GOALS AND OBJECTIVES

Family Health International's **goal** for the care and support of orphans and other vulnerable children is to:

- Improve the well being and protection of orphans and other vulnerable children, and
- Decrease the burden of HIV/AIDS on children, their families, and communities.

FHI has identified the following care and support for orphans and other vulnerable children **objectives** for its programs and activities:

- 1.) Expand current options by developing and implementing innovative, comprehensive, community-based projects for affected children, families, and communities.



- 2.) Work with governments in the continuing evolution of conscientious responses and programs that reduce epidemic impact. Through collaborative situation analysis, strategic planning, and policy development.
- 3.) Build capacity to design and implement effective orphan and other vulnerable children care and support programs.
- 4.) Provide a leadership role among partners in HIV prevention and community care at country and international levels to develop comprehensive responses and bring them to scale.
- 5.) Carefully monitor and evaluate program efforts and build sufficient feedback loops with data so continuous innovation is possible.
- 6.) Add to current knowledge with publications, workshops, and conferences.
- 7.) Build synergistic programming partnerships and collaborate with other governmental and civil society stakeholders at national, regional, and global levels to help develop networks of responses that, collectively, match the scale of the problems among children made vulnerable by HIV/AIDS.

FHI also proposes to contribute to the long-range development and adjustment of children through the development of innovative program opportunities. Through its project activities, FHI builds on current, state-of-the-art thinking and interventions to meet the outlined objectives, using project opportunities to demonstrate carefully selected solutions to strategic issues. FHI is taking advantage of its ability to link these programs with technical program activities in VCT, MTCT, and TB, and help partners do the same. FHI has also plays a significant role in helping governments conduct national planning and situation analyses (e.g., Haiti and Namibia) that contribute to advocacy efforts with governments to expand current approaches and respond with the appropriate urgency.

### **Draft Guiding Principles for OVC Programming-January 2001**

#### ***Programming principles***

1. Increase and strengthen families through community-based mechanisms;
2. Strengthen the economic coping capacities of families and communities;
3. Enhance the capacity of families and communities to respond to the psychosocial needs of orphans and vulnerable children and their caregivers;
4. Foster linkages between HIV/AIDS prevention activities, home-based care, and efforts to support orphans and other vulnerable children;
5. Target most vulnerable children and communities, not "AIDS orphans".
6. Give particular attention to how gender roles make a difference;
7. Involve children and adolescents as "part of the solution";
8. Strengthen the role of schools and education systems;
9. Reduce stigma and discrimination.

#### ***Collaborative programming principles***

10. Accelerate learning and information exchange;
11. Strengthen partnerships at all levels and build coalitions among key stakeholders;
12. Ensure that external support does not undermine community initiative and motivation.

## **IV. FHI's TECHNICAL AND PROGRAMMATIC APPROACHES**

### **Guiding principles**

In undertaking programs for the care and support of orphans and other vulnerable children, FHI subscribes to the draft International Guiding Principles coordinated by UNAIDS, UNICEF, and USAID (see box). FHI also adheres to the following core principles:

- Work to prevent HIV infection among children and adolescents made vulnerable by AIDS, and among adults, to prevent further orphaning
- Continue to advocate for care and support of orphans and other vulnerable children within the family and community context.

- Contribute to the development of and remain abreast of current national strategy in its program countries, work within it, and, where possible, undertake innovative activities to inform the further development of that strategy.
- Link care programs with other FHI HIV/AIDS programs to provide a holistic and comprehensive system of support to the families and communities with whom it is working.
- Link with other partners to coordinate, not duplicate, program efforts and provide services as yet unavailable within FHI's area of expertise.
- Become an international learning center promoting dissemination of program knowledge and diffusion of innovative ideas.

### **FHI's approach**

FHI provides programmatic and technical assistance to various levels of implementing agencies to build their capacity, and through them that of families and communities to address the care and support of orphans and vulnerable children. Recognizing that isolated programs will be able to reach only a fraction of the most vulnerable children, FHI strives to develop technical approaches that are cost effective and that other organizations can replicate. FHI also makes every effort to develop approaches that have the potential to be replicated and scaled up, so that a collaborative effort involving all key actors can reach the most vulnerable children.

### **Programmatic approach**

As noted above, there is agreement on the constituent elements of community-based programs for orphans and other vulnerable children. Prioritization of program activities will depend on community needs, abilities, and preferences as well as on the nature of sponsoring or partner organizations. The community is best able to identify target groups for interventions, although the government may wish to select target regions or communities for program implementation.

While thinking on the issue has been dominated by the 1997 and 2000 editions of *Children on the Brink*, they consolidate existing knowledge from a wide range of sources. According to both versions, five basic strategies for intervention are essential:

1. Strengthen the capacity of families to cope with their problems;
2. Mobilize and strengthen community-based responses;
3. Increase the capacity of children and young people to meet their own needs through access to quality education, protection from exploitation and excessive labor, and building the capacity of children to care for themselves;
4. Create an enabling environment for affected children and families through such activities as ensuring basic legal protection through laws and policies to protect women and children, decreasing stigma, and behavior change interventions;
5. Ensure that governments protect the most vulnerable children and provide essential services.

FHI concentrates its programming resources on the first four strategies and addresses the fifth through advocacy, partnerships, and linkages. In addition, FHI synergizes its programmatic responses

through linkages with its other projects in the prevention, care, and support continuum and the adherence to the following considerations for the design of such programs:

- **Emphasizing community care rather than institutional care:** Long-term institutionalization of children in orphanages and other facilities is not a desirable solution to the impacts of HIV/AIDS. Resources expended to fund institutional care for a single child can assist scores of children if used effectively to support a community-based initiative. The institutionalization of children separates them from families and communities and often delays healthy childhood development. FHI's priority is to strengthen communities to continue to care for their children and facilitate the reintegration of children into families and communities, making sure that health and viable living arrangements can be made.
- **Strengthening the care and coping capacities of families and communities:** FHI recognizes that the first line of response to the needs of children affected by AIDS comes from extended families. Strengthening the capacity of communities to fill the widening gaps in the safety net traditionally provided by the extended family is what FHI sees to be the most efficient, cost-effective, and sustainable way of assisting orphans and other vulnerable children. Families and communities also play a crucial role in the identification of children who are most in need, both those affected by AIDS and other vulnerable children (e.g., orphans due to causes other than AIDS such as war and other illnesses, children living in extreme poverty, street children etc). Community members know best who these children are and what their needs are and through a process whereby they identify them and building their capacity to improve their well-being responsibility and ownership is increased, stigma attached to being an "AIDS orphan" is decreased and children who are most in need are attended to.
- **Involving children and youth as part of the solution, not part of the problem:** Children are not simply a passive, powerless target group to be aided, but capable actors and important resources to engage in a community response to AIDS. Actively involving children in care initiatives can build the children's own sense of self-esteem and efficacy and cultivate skills they can use in the future. Such involvement can make HIV/AIDS a concrete reality in the experience of children and youth, help them see that they can make a difference and are needed, and increase their willingness to avoid behaviors that increase their own risk of HIV infection.
- **Building broad collaboration among key stakeholders in all sectors:** FHI uses broad networks and targeted advocacy to involve government, civil society organizations, and NGOs in shared initiatives of community action for orphans and other vulnerable children, and enables partnerships between activities in complementary sectors.
- **Applying a longterm perspective:** FHI recognizes that children will continue to be affected by AIDS for decades to come. Due to the scope and scale of the epidemic, sustainable and replicable approaches are crucial in the design of programs. Although material assistance is important, FHI strives to proceed with caution so that community projects are not driven by material support but by ownership and responsibility.
- **Integrating with other services:** Since the problems of orphans and other vulnerable children begins well before the death of their parents, FHI recognizes the importance of initiating care for children affected by AIDS starts at the earliest point possible. This can be achieved through the integration with and use of home care, VCT, hospice, hospital, and MTCT programs as entry points. It is also necessary to strengthen relationships between community programming, social

welfare, and basic services in such other sectors as health and education for holistic and sustainable program design.

- **Linking care and prevention:** Orphans and other vulnerable children are themselves at high risk of HIV infection due to economic hardship and loss of parental care and protection. For this reason alone, FHI maintains that care programs should include a strong prevention component targeted at children and youth.

## Technical approaches

FHI's strategic framework for HIV/AIDS care and support highlights the importance of providing a continuum of care for AIDS-affected families and children. Four domains are linked: medical care (diagnosis, treatment, prevention of secondary infection); psychosocial care (VCT, PLWHA associations); socioeconomic support (community safety nets, home care); protection of human rights, including legal support (protection of inheritance, reduction of abuse and stigma); community involvement; and referral mechanisms.

FHI believes that care and support for improving the well-being of orphans, children affected by AIDS, and other vulnerable children must be family/community-centered, comprehensive and tailored to specific community and national context. FHI also recognizes that to improve the well-being of these children programs should be linked or integrated with other HIV/AIDS programs and the process of developing activities needs to be connected to specific technical areas. These include reviewing and strengthening national policy, developing national strategies, and developing rational systems of care that include the definition of types and standards of care for orphans and other vulnerable children as defined by national bodies and community members. FHI contributes to this endeavor through technical assistance for the development of a process whereby key stakeholders are involved and includes:

- The use of a participatory strategic needs assessment that states clear objectives, outlines the technical areas and geographic coverage, and provides definitions of the process and skills needed to carry out the assessment.
- A written plan based on an in-depth understanding and overview of the problems faced by orphans and other vulnerable children, their families and communities, the context of these problems, traditional and current coping strategies and relevant services, laws and policies. It should also include an initial mapping of the most seriously affected populations and service areas of existing programs.

Interventions to address the needs of orphans, children affected by AIDS and other vulnerable children must solicit community and national identification of the most urgent problems and their causes, coping strategies, and potential intervention strategies and measures. It is also important to include key intervention points, information and sources for ongoing monitoring, and key strategies for documenting and disseminating lessons learned.

At the community level community members and key stakeholders should be assisted to identify the constraints to the well-being of children, activities to address their needs, and monitoring and evaluation mechanisms to identify successful aspects and those that need to be modified. Technical expertise offered from FHI for the above includes:

- Community mobilization in collaboration with ministries, religious bodies, and other NGOs to build systematic efforts to mobilize and strengthen community-level capacities through use of, but not limited to, participatory methodology, capacity building, and sensitization;
- Community capacity building including organizational skills, care-giving and counseling skills;
- Psychosocial care for children, parents, and caregivers; access to or provision of quality basic services, including health, education, and shelter;
- Addressing HIV/AIDS within integrated management of childhood illness (IMCI) programs;
- Integration of community care with technical services (VCT, prevention, MTCT, HIV/AIDS home care, hospice care);
- Advocacy, for community mobilization and to build government commitment to the issue through, but not limited to, the documentation of lessons learned, lobbying for rights of children as provided in the convention on the rights of the child;

Recognizing the need for a comprehensive and collaborative response to mitigate the impact of HIV on children and their communities, FHI creates partnerships with organizations that have expertise in the areas of income development; household security, including food security; income security; and vocational development.

## V. ILLUSTRATIVE ACTIVITIES

FHI has programs for orphans and other vulnerable children in 9 countries in the three major affected regions (Africa, Asia, and the Caribbean). Below are some examples of ongoing activities in which FHI is providing programmatic and technical assistance in the area of care and support for orphans, children affected by AIDS, and other vulnerable children.

**The Zambia Strengthening Community Partnerships for the Empowerment of OVC project (SCOPE-OVC), implemented by CARE/Zambia and Family Health Trust**, which provides an illustration of FHI's approach to the development of community-based care for orphans and other vulnerable children. This is a multisectoral approach whereby SCOPE is working with 9 districts to mitigate the impact of HIV/AIDS on children and build community capacity to address the needs of OVC. This approach is used to strengthen district and community OVC committees; build upon and expand the effectiveness and efficiency of local and community-based organizations, churches, ministries, and the private sector; and mobilize, scale up, and strengthen community-led responses and programs benefiting OVC. Steps for project implementation include community mobilization, economic strengthening, psychosocial support, advocacy, and increased access to education and health care.

- Development of a SCOPE-OVC Advisory Committee including some of the following key players: SCOPE-OVC project manager, representatives from USAID, UNICEF, Children in Need Network, Zambia Integrated Health Project, FHT Executive and key line ministries of health. Development of terms of reference including providing broad recommendations on project directions, harnessing political support at both national and district levels, fostering government partnerships, forging relationship with National OVC Taskforce, and sharing information pertaining to OVC work.
- Formation/strengthening of District and Community OVC committees (capacity inventories; operational guidelines with clearly defined roles responsibilities and relationships; and strengthened linkages with other district and community level partners);

- Community mobilization (through the use of participatory techniques including social mapping, livelihood diagrams, Institutional -Venn diagrams, ranking, and problem tree communities). Capacities are built to identify problems related to OVC, solutions to the identified problems, current coping strategies, areas that need support, and local resources that can be mobilized to address OVC issues.
- Development of a Grants Management Toolkit that provides information on how to apply for grants, the different categories of sub-grants, potential areas of funding, criteria for awarding sub-grants and the process involved.
- Economic strengthening (identification of and linkages to micro-economic organizations to begin geographical overlapping of micro-economic activities in SCOPE-OVC districts).
- Quantitative and qualitative baseline, including three phases—organizational capacity inventories, status of households, and well-being of children—to gather baseline data for evaluating the effectiveness of the SCOPE OVC project in the identified target sites of Zambia.

**Siyawela (crossing over) OVC project of Hope Worldwide, Soweto, South Africa.** Siyawela facilitates the formation and strengthening of care and support for OVC into existing community-based prevention and care activities. It increases the capacity of communities to care for OVC and strengthen referral systems to allow for a continuum of care through a network of support groups, and linkages with the Perinatal HIV Research Unit at Chris Hani Baragwanath Hospital and surrounding midwifery clinics with MTCT interventions. Steps for project implementation include:

- Strengthening staff management and technical capacity (technical trainings, establishing community resource centers);
- Participatory research (capacity mapping, focus group discussions with key stakeholders and community members, consensus workshops, and disseminating findings);
- Community network strengthening (OVC committee formation; development of roles, responsibilities, and strategies; establishment of partnership/referral data base; and capacity building of OVC committees in identified priority areas);
- Increased care and support for OVC (strengthening of coordinators' capacities in childhood development, care for children living with HIV, development of referral system between committees and support networks); and
- Psychosocial support for women and children affected by HIV (development of referral network to specialized services for psychosocial support; support groups for people living with AIDS, including closed groups for pregnant women with HIV, capacity-building in play therapy, bereavement counseling, care for caregivers, and disclosure and future planning for children with terminally ill parents).

**Nyemo II Counselling Centre, Cambodia** provides support for community women, many of whom are living with HIV or have already developed AIDS, and their children. Services include kindergarten and literacy, life skills, and nutrition education. Nyemo also provides mechanisms to help women living with HIV and children reintegrate into their extended families strengthen the future well-being of children.

## **VI. INTERVENTION-LINKED RESEARCH**

Many potential research issues linked to the interventions described in this strategy can be derived from the programmatic issues listed above. Key research issues identified to address affected children, families, and communities include:

1. Key elements in systematic mobilization and building of communities around HIV/AIDS and OVC issues.
2. Establishing referral systems that link community-based programs with technical services in HIV/AIDS, TB, and STDs;
3. Developing approaches to set standards and improve the quality of care of pediatric AIDS care, especially for the underserved population of children between 5 –15 years of age;
4. Community-based care as women's work; (and using the development of community care as a development opportunity to empower women and girls)
5. Barriers to the longevity of community-based care organizations;
6. Participation of adolescents and young people in prevention, care and support;
7. Use of small projects as bases for research and data collection;
8. Community-based monitoring and evaluation.
9. Lessons to aid replication and scaling up

From FHI's standpoint, intervention-linked research should stress:

- Improving the relationship of community-based care to programs of voluntary counseling and testing, and reducing mother-to-child transmission of HIV;
- The role of community-based care in improving compliance with TB treatment regimens;
- Addressing OVC activities within a home-based care and support context;
- Contextual factors, especially children living in crisis situations such as war;
- The extent to which families are really breaking down (although program people say they are breaking down, the number of street kids does not indicate it);
- Community incentives needed to provide care;
- Long-term psychosocial impact of AIDS on children;
- What kind of care is appropriate for children in different circumstances;
- The integration of services into special programs.

## **VII. MONITORING AND EVALUATION**

Rapid expansion of systems acceptable to families at the grassroots level has proven to be a good initial strategy for countries that want to develop or strengthen systems of family and community care. After gaining experience, evaluating the effectiveness and cost of different approaches can help improve quality. Evaluation and monitoring planning can help programs adapt to provide better services by assessing the communities' evaluation needs, resources, capabilities, and different priorities.

To evaluate effectiveness, data are needed on the coverage of existing services and on processes, including methods of training and implementation. Effectiveness is linked to outcomes by comparing

the well-being of children in different types of care but these data have not yet been compiled. Cost data are even more elusive. In general, institutions provide the most expensive care, government-run community-based programs the least expensive care, with expatriate-financed community-based programs and mission and hospital programs hovering in the middle of the range. In each of these categories there is a wide range of costs depending on the level of services and goods provided by the program.

For either type of evaluation a basic data gathering system is necessary. The most extensive data on the impact of the AIDS epidemic are being collected by USAID-sponsored Demographic and Health Surveys, World Bank Poverty studies, and small area research studies. As critical as they are to national planning, only four countries in eastern and southern Africa (Kenya, Mozambique, Zambia, and South Africa) have up-to-date orphan estimates. New censuses—the first showing epidemic's impact—will provide information on household change in another few years.

Data on other populations of children not in households (street children, child labourers, institutional populations) are only occasionally collected, but should be collected routinely and often to monitor the shift of children between types of care or outside of caregiving systems. The relative numbers of children in different types of care may be the most robust indicator of overall demographic pressure and social change resulting from increased adult mortality.

The unprecedented nature and impacts of the HIV/AIDS pandemic necessitate the ongoing monitoring of outcome and impacts, evaluation of interventions, and research on strategic issues. To ensure that interventions actually make a difference in the lives of vulnerable children and families, they must include mechanisms to measure their impacts which, in turn, provide a basis for adjusting interventions to make them more effective. These mechanisms should also include participatory appraisal methods that community residents can use to measure impacts of HIV/AIDS and the effectiveness of responses. But the indicators used to measure the outcome of community mobilization cannot be predetermined without undermining the sense of ownership and responsibility that are essential to sustaining community action.

Communities must decide who and what they are most concerned about, what factors determine vulnerability in that community, what community members are willing and able to do in response, and how to measure the results of their efforts. Several agencies are developing indicators to evaluate family and community care programs—including process indicators to measure program implementation and follow up, and outcome indicators to look at the impact of these programs on child and family health, education, income, and nutrition.

Illustrative indicators include:

- Percent of OVC committees with multisectoral representation six months after project startup;
- Percent of OVC committees formed and/or strengthened six months after project startup;
- Percent of OVC placed in school measured by number of school-age OVC placed in school (currently attending) versus number of school-age OVC previously not in school at baseline;
- Percent of OVC returned to school measured by number of OVC returned to school (currently attending) versus number of OVC previously attending but with a period of not attending at baseline;
- Percent of household expenditure used on food, health, and education;
- Percent of households who spend greater than 75 percent of total expenditure on food measured against the total number of households, 75 percent based on current literature of country context;



- Percent of OVC less than two negative standard deviations on height for age against National Child Health Survey (NCHS). Measured by the number of OVC less than two standard deviations on height for age from reference mean (NCHS) age 0-60 months compared with the number of OVC 0 – 60 months;
- Percent of OVC less than negative 2 standard deviation weight for height against National Child Health Survey (NCHS). Measured by the number of OVC less than two standard deviations on weight for height from reference mean (NCHS) age 0-60 months / the number of OVC 0 – 60 months; and
- Percent of OVC receiving appropriate medical care.
- Percent of OVC receiving appropriate psychological care.

## **VIII. LINKAGES AND PARTNERSHIPS**

FHI constantly searches out partnership opportunities, emphasizing national and local partners. In searching for partners, FHI links with other organizations to provide technical assistance and tools, and technical services, such as strategic planning, effective community mobilization, VCT, MTCT prevention, TB prophylaxis, and monitoring and evaluation. Other partners with expertise in microfinance and household livelihood security are also engaged in developing community-based projects for orphans and other vulnerable children.

At a national level FHI maintains that it is crucial to support and build partnership with key stakeholders at various levels in supporting the well-being of orphans, children affected by AIDS, and other vulnerable children. Without such partnerships it is not possible to create an enabling environment, strategic plan, or adequately address crucial aspects of increasing the capacity of countries to care for and support these children and the communities in which they live. FHI's national level partnerships include:

- Ministries with responsibilities in such areas as health, social welfare, education, nutrition, community development, youth, gender, agriculture, planning, and registration of NGOs;
- Child- and family-oriented NGOs;
- Organizations engaged in grassroots development;
- Religious bodies;
- University departments with expertise in such areas as social welfare, social research, public health, education, nutrition, demography, anthropology, and public policy; and
- Associations and support organizations for people living with HIV/AIDS

On the international level, FHI maintains close relationships with USAID, UNICEF, and UNAIDS. FHI is expanding its role in contributing to and disseminating current knowledge and thinking on these issues through publications, workshops, contributions to such international Web sites as CABA (Children Affected By AIDS), and participation on international strategy development bodies.

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## **E-mail list-serves**

Children Affected by AIDS (CABA)

- To send a message to the forum: [CABA@forumone.com](mailto:CABA@forumone.com)
- Browse previous postings at: <http://www.synergyaids.com/caba>
- To join or leave the forum, email [caba-request@forumone.com](mailto:caba-request@forumone.com) with the message "subscribe caba" or "unsubscribe caba"
- Reproduction welcomed, provided source and forum email address is quoted
- Children Affected by AIDS (CABA) is provided and managed by The Synergy Project ([www.synergyaids.com](http://www.synergyaids.com)), a USAID Contract

CABA posts documents on its Web site, rather than sending them out as attachments. Those who have difficulty accessing the Web site but who want a posted document can send a request to the CABA Coordinator and request to receive it as an e-mail attachment by sending a request to <mailto:caba-request@forumone.com?subject=help> .

Psychosocial Support for Children Affected By AIDS (PPS-CABA)

To send a message to the forum: [pss-caba@hst.org.za](mailto:pss-caba@hst.org.za)  
To join; send a message to: [join-pss-caba@hst.org.za](mailto:join-pss-caba@hst.org.za)  
To leave; send a blank message to: [leave-pss-caba@hst.org.za](mailto:leave-pss-caba@hst.org.za)

Project description available at: [www.masiye.com](http://www.masiye.com) or [info@masiye.com](mailto:info@masiye.com)

The PPS-CABA forum is managed and moderated by Salvation Army Masiye Camp ([www.masiye.com](http://www.masiye.com)) with technical support from Health & Development Networks ([www.hdnet.org](http://www.hdnet.org)) and Health Systems Trust ([www.hst.org.za](http://www.hst.org.za)). Financial support comes from the partners of the think tank - Swiss Agency for Development and Cooperation (SDC) and Novartis Foundation for Sustainable Development and is moderated under Health & Development Networks standards and guidelines.

