

**The Situation of  
Orphans in Haiti:  
*A Summary  
Assessment***

A Preliminary Assessment of Orphans and  
Vulnerable Children with a Focus on Children  
Affected by HIV/AIDS

*FHI implements the USAID IMPACT Project in partnership with the Institute of Tropical Medicine Management Sciences for Health ♦ Population Services International ♦ Program for Appropriate Technology in Health ♦ and the University of North Carolina at Chapel Hill.*

*This work was supported by the United States Agency for International Development (USAID) as part of Family Health International's (FHI) Implementing AIDS Prevention and Care (IMPACT) Project (Cooperative Agreement HRN-A-00-97-00017-00) and does not necessarily reflect the views of USAID or FHI.*

## ACRONYMNS

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AZT	Zidovudine
BND	Bureau National de Developpement
CAM	Christian Aid Mission
CEHN	Chambre de l'Enfance Necessiteuse Haïtienne
CRS	Catholic Relief Services
EMMUS	Enquête Mortalité Morbidité et Utilisation des Services
FHI	Family Health International
FOSREF	Fondation pour la Santé Reproductrice et l'Education Familiale
ILO	International Labor Organization
MSH	Management Sciences for Health
MSPP	Ministère de la Santé Publique et de la Population
NGO	Non-governmental organization
NOTF	National Orphans Task Force
PLWHA	People living with HIV/AIDS
POZ	Promoteurs de l'Objectif ZeroSIDA
SCF/UK	Save the Children Foundation/United Kingdom
STI	Sexually transmitted infection
TB	Tuberculosis
VCT	Voluntary counseling and testing (for HIV)

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# EXECUTIVE SUMMARY

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## **Background/Purpose**

With an estimated 1.2 million orphans and vulnerable children (OVC) in the country and an HIV prevalence of 7.7% of the population, the Haitian government, donors and other stakeholders have realized the importance of strengthening their interventions to reach these children. At this time, the Ministry of Health is involved in a strategic planning process that will result in a new five-year plan to address this tragedy. At the same time, USAID/Haiti recognizing the urgency of this issue, requested FHI/IMPACT assistance in assessing the situation. This report is the result of the efforts of an FHI/IMPACT-fielded team which conducted meetings, interviews, a literature review and field visits over a period of two weeks in April 2000. USAID/Haiti and others will use this report to inform the internal and external processes of prioritizing and designing a strategic and expanded response targeting OVC. It is a first step in developing a body of knowledge about OVC and their families in Haiti. Additionally, it provides information that will support development of a policy environment supportive of community-based programming.

## **HIV and OVC in Haiti**

The poorest nation in the hemisphere, more than 70% of Haitians live in poverty with an estimated annual income of approximately \$400 (PRB Population Data Sheet 1999). The statistics paint a grim picture of the situation in Haiti in general and for its children in particular. Haiti's HIV prevalence rate is the highest in the region. Estimates are that there are over 300,000 HIV positive men, women and children in the country with 45,000 AIDS-related deaths per year. Each year some 5,000 babies are born infected. Forty percent of the population is under the age of 15 and as many as 25% of these children may be classified as extremely vulnerable. Between 5 and 7% of children have already lost one or both parents and over 7% live in families with an infected member. As a result, Haiti has and will continue to have a growing number of disadvantaged young people and an ominous threat to the country's future economic development.

## **Assessment of the Situation and Response**

Only one quarter of Haiti's vulnerable children have lost one or both parents. The remaining 900,000 plus are children in female-headed households, fostered children, children in institutions, children living in families with an HIV-positive adult, HIV-positive children, street children, child laborers and others. Studies indicate that 25% or more of Haitian families included at least one child whose parents are not part of that household. Coupled with the economic decline of the past decade, these factors put the children at even greater risk. These children suffer higher rates of mortality and malnutrition. Fewer are immunized and many must drop out of school. Although some

data indicate the pandemic may recently have plateaued, the economic and social problems faced by the children and families affected by HIV/AIDS will not diminish for at least another 15 years.

If this pandemic has plateaued, it is in part due to the efforts of governmental and non-governmental organizations. The government's proposed new strategic plan includes developing a guide for family and community care. NGOs, including CARE, Save the Children, CRS, MSH, ILO, UNICEF, and local institutions currently support various types of programs for OVC including institution-based, fostering and community-based care. An estimated 200,000 children live full or part-time in institutions and reliance on these institutions may be increasing. Unfortunately, funding for OVC interventions in 1999-2000 is only at 10% of the level it was at from 1990 to 1995. More than half of OVC are absorbed into families and communities however the stigma, economic strains and organizational challenges of caring for these children limit this response.

## **Conclusions**

- Despite the decades-long existence of AIDS in Haiti, support for adults and children living with HIV/AIDS is not strong, either at the institutional level or at the family and community level. Services that are provided and planned are not well known.
- Several significant barriers remain to be addressed as this new strategic planning and policy development exercise gets underway. Denial is strong and PLWHAs experience high levels of stigma and discrimination.
- Haiti has a number of strengths for programming to contain the spread of HIV/AIDS in the country. The government is committed to establishing a broad, multisectoral HIV/AIDS policy and has started the process of its development.
- At present, family and community care appears to be viable for the majority of vulnerable children in Haiti, although orphanages and the food security program provide valuable safety nets for vulnerable children and families.
- Research on a large group of children made vulnerable by the HIV/AIDS epidemic is not currently being addressed in a systematic manner.

## **Recommendations**

- The gathering of additional data is essential in order to have a clear, more comprehensive picture of the status of orphans and vulnerable children.
- A community-based prevention and care approach should be the cornerstone of the plan in Haiti. While some essential elements of effective AIDS control have been put into place or are being expanded, more needs to be done to link prevention and care.
- A widespread response from the health and education sectors that supports a policy environment that will lead to increased access to health services is necessary to keep conditions from deteriorating further. Coordinating and stimulating development of policy and response for families and children affected by HIV/AIDS is of particular importance. Issues of care, both for PLWHAs and their children, should be featured in the new National AIDS Plan and clearly linked with strategies for prevention.

- A community-based monitoring system should be developed.
- Introducing community and family support programs now that include psychosocial, organizational and economic interventions will lessen the impact of this social problem as the number of orphans increases.
- Haiti should strive to decrease its reliance on expensive institutions but link orphanages with communities to pioneer community-based outreach programs, especially for HIV-positive children.

# I. ASSESSMENT BACKGROUND AND METHODOLOGY

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## A. Background

The 1997 World AIDS Day release of *Children on the Brink* was a wake-up call for the international development community. The report estimates that there will be more than 40 million orphaned children in 23 study countries (including Haiti) by 2010, largely due to the HIV/AIDS epidemic. In addition to its detrimental impacts on adult and child health in the region, the report describes the deleterious socioeconomic impacts of increased AIDS mortality over the next 10 to 20 years. *Children on the Brink* portrays the scale and urgency of this demographic event in an unprecedented fashion, a clear picture of the massive impact the pandemic will have on children, families, societies, and economies in heavily affected countries through the coming three decades.

In Latin America and the Caribbean, the most HIV/AIDS-affected country is Haiti. Not only does the country record the highest seroprevalence estimates in the hemisphere, but health indicators signal the extreme vulnerability of children under 15, who comprise more than 40% of its total population. Although great progress has been made thanks to the work of many dedicated NGO and government organizations, the economic and social problems faced by affected children and families will not diminish for at least another 15 years.

Since the release of *Children on the Brink*, the United States Agency for International Development (USAID) has been working with UNAIDS, UNICEF, and other international organizations to intensify programming activities for orphans and other vulnerable children in HIV/AIDS-affected countries. Family Health International, under the USAID-funded IMPACT project, was requested by USAID/Haiti to manage this preliminary assessment of orphans and vulnerable children. For the purposes of this document, vulnerable children refers to children who are vulnerable to high morbidity and mortality, and/or face a loss of basic human rights. This document also refers to various categories of orphans: maternal orphans have lost their mothers; paternal orphans, their father, and double orphans have lost both biological parents. A foster child is a child who may or may not be an orphan but is taken care of by a person who is not a biological parent.

## B. Objectives and Methodology of the Consultation

The objective of this assessment is to begin a preliminary analysis of the situation of orphans and other vulnerable children and families in Haiti. The importance of this analysis cannot be overstated, as it is the initial step in developing a body of knowledge about orphans and children vulnerable to HIV/AIDS in Haiti. The consultants were asked to:

1. Conduct a literature and data review;
2. Conduct a government policy review;
3. Identify and assess current activities for children affected by HIV/AIDS;
4. Investigate family and community coping and adaptation strategies;
5. Assess family and community perceptions of the problems of vulnerable children and families, and traditional support structures to help them;
6. Assess effectiveness of assistance;
7. Explore impact of descent and inheritance, gender, migration.

The last four items could not be accomplished during the consultation because they require extensive, community-based research. Instead, the consulting team identified local consultants and on-going project-based research that would produce information on family and community coping strategies during the course of project implementation. These could be included in a second edition of this assessment. Information concerning coping strategies of children, families and communities described in this assessment is based on the literature and from interviews.

To develop this assessment, the assessment team (the consultant and FHI/IMPACT staff in Port-au-Prince) discussed current programs and opportunities for expanded programming with government personnel, non-governmental organizations, UNAIDS, UNICEF and other UN agencies. They also discussed programming opportunities with USAID staff in other sectors and reviewed available literature and documentation on the issue.

This preliminary assessment meets some of the information needs of the Ministry of Health's national HIV/AIDS strategic planning process and contributes to USAID's own goals for family and community responses to the HIV/AIDS epidemic in Haiti. Investigation of alternative mechanisms to support community-based programming for children and families affected by HIV/AIDS and promotion and further development of explicit policy and strategies of support for community-based programs for families and children affected by HIV/AIDS was a priority for this assessment.

Community-based approaches are the only viable and sustainable alternative for providing care and protection for children made vulnerable by the HIV/AIDS epidemic. This is dictated by the number of children affected by the epidemic, limited service availability in the country, and the relative desirability of alternatives in terms of their impact on long term child development and economic development for Haiti.

### **C. The Assessment Team**

The consulting team was headed by Roberte Eveillard, M.D., M.P.H., FHI/IMPACT's Assistant Project Officer in Haiti. The consultant engaged for the situation analysis was Susan Hunter, Ph.D. Dr. Hunter was principal author of *Children on the Brink*, the seminal document on orphans and vulnerable children worldwide.

## II. THE HIV/AIDS EPIDEMIC IN HAITI

### A. Seroprevalence Levels and Patterns

**Infection Levels.** In 1998, a POLICY Project research team completed extensive modeling of the HIV/AIDS epidemic in Haiti. According to these estimates, some 5.4 to 7.7% of adult Haitians are estimated to be HIV positive, 4.1 to 5.8% in rural areas and 9.4 to 13.4% in urban areas. The report also estimated the number of people currently living with HIV/AIDS in Haiti to be between 260,000 to 365,000, or about 6% of Haiti's population. The number is expected to reach 263,000 to 375,000 in 2010.

These estimates were based on a variety of HIV/AIDS data collected in Haiti, the latest from a national seroprevalence surveillance study in 1996. The most recent sentinel survey was completed in Haiti in 1999, but results have not yet been released.

At 7.7%, the HIV/AIDS epidemic is already solidly entrenched in Haiti, and has reached the level of a "generalized" epidemic. The high rates of infection among younger age groups point to the same conclusion and suggest that the epidemic has been established in the country for some time and is now increasing rapidly in all age groups. However, urban/rural differentials continue to prevail, possibly due to difficulties in transportation among rural provinces.

The epidemic will be difficult to contain in Haiti because sexual behavior begins early and unprotected multiple partner behavior is common among both men and women. In addition, other sexually transmitted infections (STIs) are widespread, and this facilitates rapid spread of the virus. An attitude of denial about HIV/AIDS, lack of strong public education about the disease, and no strategies to contain it, handicap efforts to contain the disease.

**Distribution.** According to the POLICY Project's 1998 estimates of seroprevalence, four of Haiti's provinces are more seriously affected than the other five: Center, Northwest, West and North. Seroprevalence exceeds 5% in these areas, indicating a generalized epidemic. In the other five (Southeast, Artibonite, Northeast,

<b>Impact of HIV/AIDS in Haiti</b>	
<b>Seroprevalence Among 15-49 Year Olds</b>	
National	5.4 to 7.7 %
Urban	9.4 to 13.4 %
Rural	4.1 to 5.8 %
<b>People Living with HIV/AIDS in 2000</b>	
260,000 to 365,000	
<b>Annual AIDS Deaths, 2000</b>	
30,000 to 45,000	
<b>Total AIDS Deaths by 2010</b>	
1,000,000	
<b>Orphans Due to HIV/AIDS in 2000</b>	
163,000 to 235,000	
<b>TB Cases Due to AIDS since the epidemic</b>	
50,000	
<b>The epidemic is generalized within Haiti's population, meaning that it has spread beyond high risk groups into the general population</b>	
Source: POLICY Project 1998	

South and Grand Anse), seroprevalence was estimated at less than 5%. Such geographic differences, if they persist in 1999 seroprevalence data, may be useful for broad geographic targeting of HIV/AIDS programming in prevention and care.

In 1998, it was estimated that 13,000 to 18,000 Haitian children were infected with HIV. Of these, about 5,000 were infected in 1998. Some 3,820 to 5,400 new AIDS cases were estimated in children under 5. These cases are due largely to mother to child transmission which may occur in the womb or through breastfeeding. Haiti is currently participating in an international study using Zidovudine (AZT) to avert mother to child transmission, but results will not be ready for several years. It is not likely that such interventions will be widespread in Haiti for at least another 5 to 10 years.

<b>Estimated HIV Prevalence by Province</b>	
<b>Province</b>	<b>Estimated Prevalence</b>
North	13.1%
Northwest	7.6
Grand Anse	6.3
Central Plateau	5.8
Northeast	3.9%
Artibonite	3.9
Southeast	4.8
South	4.0
West	4.0

Until 1999 surveillance data is available, speculation on the possibilities of controlling the epidemic's further spread in the 15 to 49 year old age group must be limited. Current infection levels suggest that epidemic control would require large-scale commitment to prevention, including widespread voluntary counseling and testing, condom use and STD diagnosis and treatment. Given the limitations of Haiti's health services, services such as these may be difficult to put in place soon.

In addition, infection levels also suggest that in many areas of the country, programs of care for women and children need to be massive, immediate, strategically managed, and widespread. The proportions of infected adults in many areas suggest that the number of ill and dying adults and children, and the number of children orphaned, will increase rapidly over the next five years. The human and social costs of the epidemic in Haiti are already high, with 216,00 to 300,000 AIDS deaths estimated since reporting began. The POLICY Project estimated that 30,000 to 45,000 additional deaths will occur each year due to AIDS between 2000 and 2010. The total number of deaths due to AIDS in Haiti is expected to exceed one million by 2010.

<b>Prospects for AIDS Control in Haiti</b>
<ul style="list-style-type: none"> <li>-The AIDS epidemic will not be easy to contain in Haiti:               <ul style="list-style-type: none"> <li>Multiple partner behavior is common</li> <li>Condom use is scorned</li> <li>Denial is strong and pervasive</li> <li>Testing is difficult to obtain</li> <li>National AIDS Control Program is not strong</li> <li>Women's low status reduces their ability to negotiate for safe sex</li> <li>Violence and rape are common</li> </ul> </li> <li>-The impact will be severe               <ul style="list-style-type: none"> <li>Little forward planning</li> <li>Home care services are just starting</li> <li>Health services not readily accessible</li> <li>Stigma is high</li> <li>Poverty is widespread (50%)</li> </ul> </li> </ul>

Prospects for successful HIV/AIDS control in Haiti diminished with reductions in spending on prevention and care in the mid-1990s. Community-based research tells us that there is little talk of HIV/AIDS even when the community is aware of a member's illness because stigma is still very high. The children are often neglected by hospital and orphanage staff because they assume the infants will soon die.

Not only will the social costs be high, they will be long term. Even if incidence (new infections) stabilizes after 2000, infection levels will remain high through at least 2005, deaths will not level until after 2010, and the proportion of children orphaned will remain disproportionately high through at least 2020.

The epidemic in Haiti may be difficult to manage for a number of reasons:

1. The small size of the population makes it hard to absorb additional mortality. There is no dilution of mortality impact, which is likely to escalate rapidly in the next few years given the epidemic curve or age;
2. Difficulty in communication and travel within the country means that services are difficult to deliver in many areas;
3. Loss of skilled personnel will have a severe effect;
4. Studies of population impact, family and community coping, and studies of sectoral impact are lacking to inform policy decisions in the country;
5. Developing social systems in health, education and welfare will not be flexible in absorbing loss of personnel and increased demand;
6. Existing economic imbalances will make the impact on the poor increasingly apparent.

Haiti's efforts to improve adult and child health are likely to deteriorate given the impact of HIV/AIDS. Haiti's infant, under 5 and maternal mortality rates will increase from already high levels. Recent U.S. Census Bureau projections estimate a drop of life expectancy from 58.8 to 54.4 by 2010.

Haiti needs a multi-sectoral HIV/AIDS plan with firm leadership to make it effective. Fortunately, such a plan is under development by the MSPP and UNAIDS, working with partners in several sectors.

<p><b>The Epidemic in Haiti May Be Difficult to Manage</b></p> <ul style="list-style-type: none"><li>_Small population</li><li>_Difficulty in communication and travel makes services difficult</li><li>_Skilled personnel lost to the epidemic will be harder to replace</li><li>_Population impact, orphan estimates, and studies of sectoral impact are not in place</li><li>_Developing social systems will be less flexible</li><li>_Economic imbalances make impact on poor much more apparent</li></ul>
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## B. Contribution to Adult and Child Mortality and Morbidity

The social and economic costs of the epidemic are already high in Haiti, although they have not been quantified in a multisectoral study. Impact on child and adult mortality and morbidity over the next 20 years will be very high. Estimates completed by United States Census Bureau 1998 show the potentially severe impact of the epidemic on population growth, infant and adult mortality and life expectancy and death.

### *Contribution to Infant and Child Mortality*

According to these estimates, infant mortality in Haiti will not decrease as much as expected between 1998 and 2010 because of HIV/AIDS. Through 2010, HIV/AIDS is expected to increase infant mortality levels 10 to 20% over what they could have been without HIV/AIDS. The 1994/95 EMMUS II recorded infant and under 5 mortality levels of 87.1 and 130.6 per 1,000 live births respectively. These levels are already increasing due to HIV/AIDS (vertical transmission), and are estimated by the U.S. Census Bureau to be 95.6 and 155.7 in 1998. With the impact of HIV/AIDS, their decrease by 2010 will be 20% less than expected. In other words, they will decline to 83.4 and 129.1 instead of to 80.1 and 119.0 respectively by 2010.

The increases in infant and child mortality may be even greater in areas where localized infection rates are higher or maternal and child health service weaker. The increase in infant and under 5 mortality will be due to the HIV infection of children born to HIV positive mothers, and will occur unless major inroads are made to improve the health and wellbeing of infants and children who are not HIV positive. Uganda has demonstrated that it is possible to reduce infant and child mortality despite high HIV seroprevalence rates (12% nationally). However, like many other countries, Haiti has not received comparable financial resources.

### **Demographic Impact of the Epidemic on Haiti**

- \_20% increase in infant and child mortality
- \_Possible increase of maternal mortality by 10% (currently estimated at 600/100,000)
- \_Adult mortality may double
- \_Increase child and adult morbidity (illness)
- \_Increases in TB
- \_Lower fertility (20%)
- \_Reduction in population growth
- \_Change in population structure resulting in severe increases in dependency ratios (loss of productive adults, more children, more older persons)

### **Impact of HIV/AIDS on Haiti Estimates of Key Indicators, 1998 and 2010**

	<b>1998</b>	<b>2010</b>
Growth rate		
With AIDS	1.5	1.7
Without AIDS	2.0	2.1
Life Expectancy		
With AIDS	51.4	54.4
Without AIDS	55.5	58.8
Infant Mortality Rate		
With AIDS	99.0	83.4
Without AIDS	95.6	80.1
Under 5 Mortality		
With AIDS	155.7	129.1
Without AIDS	145.9	119.0

**Source:** U.S. Census Bureau 1998  
Population estimates

### *Contribution to Maternal Mortality*

Haiti's maternal mortality is estimated to be between 600 and 1,000 per 100,000. Although conclusive data as to the impact of HIV/AIDS on maternal mortality has not been available to date, it is expected that ongoing studies will yield Haiti specific data.

### *Contribution to Adult Mortality*

There is no direct measure as yet of the impact of AIDS on adult mortality in Haiti, but we know from direct studies in other countries that adult mortality doubles and triples (depending on the base rate) when HIV prevalence in a country reaches 10%. Since Haiti's estimated prevalence rate is 7.7%, the impact on mortality in the 15 to 49 year age group is already becoming profound. The U.S. Census Bureau estimates a loss of about four years in adult life expectancy in Haiti between 1998 and in their projections for 2010.

### *Contribution to Morbidity*

HIV and AIDS have extremely negative impacts on adult and child health. At current infection levels, 3,000 to 6,000 Haitian infants contract HIV each year. An estimated 90% of these children die within their first year of life. Surviving children often experience many more illnesses and developmental difficulties than HIV negative children, which means an additional burden for their caregivers. The economic cost of HIV/AIDS-related illnesses suffered by adults is high, often with a more severe economic cost on employers than their eventual deaths. An estimated 50,000 cases of TB in Haiti have been attributed to HIV/AIDS since the epidemic. In heavily infected countries, tuberculosis (TB) has also been shown to increase in HIV negative children living with HIV positive/TB positive adults.

#### **How children are 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

### III. THE SITUATION OF ORPHANS AND CAREGIVERS IN HAITI

#### A. Prospects for Children in Haiti

The increase in adult deaths in Haiti due to HIV/AIDS has led to an increase in the number of children who are orphans, but current levels and future trends are clearly a matter of debate. In addition, while orphaning is a threat to child well being and protection from the HIV/AIDS epidemic, it is not the only threat. The prospects for children in Haiti will also worsen in a number of other ways because of HIV/AIDS:

1. Infant and child mortality rates will increase by 10 to 20% above expected future levels;
2. Many more infants will be born HIV positive;
3. A large proportion of Haitian children are living in families where a member is HIV positive, meaning that they are exposed to other infectious diseases in addition to the trauma resulting from caring for ill family members.

**Estimated Orphans.** There are three sets of estimates of orphans in Haiti: 1994/95 EMMUS data; estimates for 2000 and 2010 from the 1998 POLICY Project study; and estimates for 1990, 1995, 2000, 2005 and 2010 from the 1997 U.S. Census Bureau study, *Children on the Brink*. While current estimates are comparable, projections for 2010 vary widely (see box at right and chart on the following page). There are several reasons why:

- a. Orphan estimates depend on projections of future *seroprevalence levels*,

#### Orphans and Children Affected by HIV/AIDS Estimates for Haiti

##### % of children under 15 orphaned, EMMUS

###### 1994/95

Mother Dead	1.5 %
Father Dead	4.5 %
Both Dead	1.4 %
<b>Total</b>	<b>7.4 %</b>

##### Estimated Orphans in Haiti, All Causes, Children on the Brink (Number and Percent of < 15s)

###### 2000

Maternal and double	189,450 (5.9%)
Paternal	231,550 (7.3%)
<b>Total</b>	<b>421,000 (13.2%)</b>

###### 2010

Maternal and double	170,807 (5.1%)
Paternal	139,751 (4.2%)
<b>Total</b>	<b>310,558 (9.3%)</b>

##### Estimated Orphans, AIDS Only, 2000 —POLICY Projections (Number and Percent of < 15s)

###### 2000

Low Scenario, Total	163,000 (5.6%)
High Scenario, Total	235,000 (7.4%)

###### 2010

Low Scenario, Total	263,000 (8.6%)
High Scenario, Total	375,000 (12.2%)

##### HIV Positive Children

2000: 20,000 (.7 % of children <15)
2010: 15,000 (.6 % of children <15)

##### Children Living in Families with HIV/AIDS, 2000

Number: 250,000
Percent: 7.7% of children <15

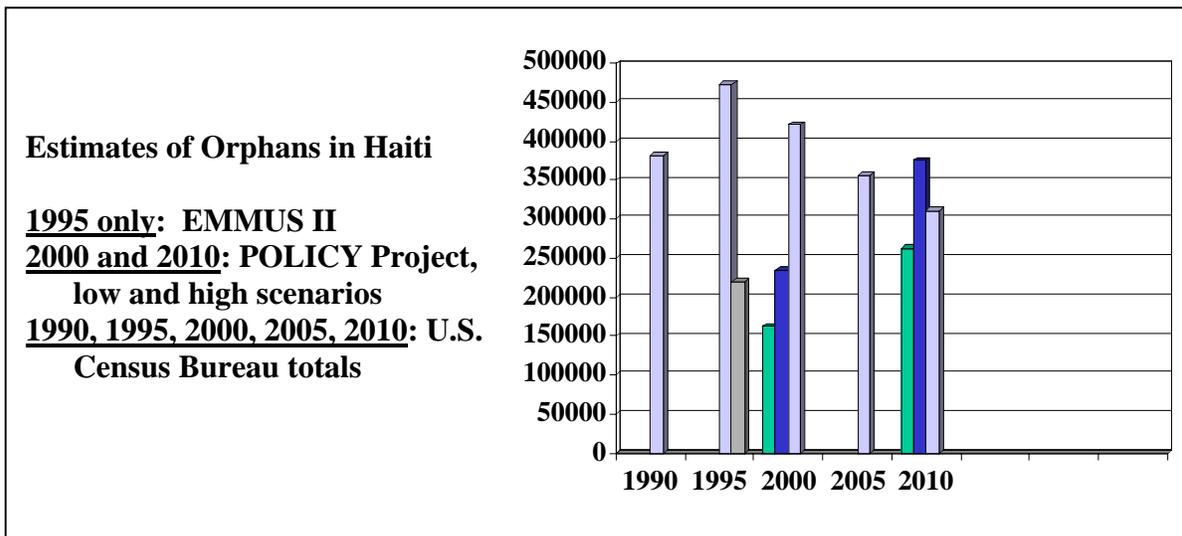
##### Children Affected by HIV/AIDS, 2000

440,000 – (13 – 15 %)

Note: The estimates of orphans and children living in families affected by HIV/AIDS overlap. The orphan estimates and those of HIV positive children do not, so the total number of children affected by HIV/AIDS is the total of orphans plus HIV positive children

which in turn depend on a variety of variables in the epidemic models used (date when the epidemic began, patterns of spread, proportion of men and women infected). Projection of the future trajectory of the epidemic is the principal cause of differences in the orphan projections.

- b. They also depend on predicted *fertility rates* (HIV positive and HIV negative women) and overall growth patterns of the population, including the proportion of children under 15. Firm, scientific evidence for reduced fertility among HIV positive women is new and is only now being incorporated in the U.S. Census Bureau's new Children on the Brink 2000 projections. The POLICY Project did not include fertility reductions in their projections;
- c. Projected *mortality patterns* also play a role (total rate, proportion due to AIDS, mortality rate of children).
- d. Orphan estimates usually do not include HIV positive children because most die before age 1 year.



According to the model used in the 1997 *Children on the Brink*, the proportion of children orphaned in Haiti peaked in 1995 and began to decline thereafter due to reductions in HIV incidence and prevalence and to reductions in overall fertility rates. HIV prevalence data collected after these estimates were completed show that this is not the case; however, recent data indicate that prevalence may be plateauing, at least in some areas.

***Different Categories of Orphans*** The only source of actual data on orphan levels in Haiti comes from the 1994/95 EMMUS II. According to this data, 7.4% of the children under 15 years living in survey households were orphans (1.5% with mother dead, 4.5% with father dead, and 1.4% with both mother and father dead, or double orphans). While these data provide a good reflection of the national pattern of maternal, paternal and double orphaning, they are not good indicators of the total number of orphans because children who are not in households with adults are not included. These

children are among the most vulnerable, because they are living on their own, in child-headed households, in institutions, or on the street.

Although demographers generally prefer to estimate maternal and double orphans for methodological reasons, the number of children who are paternal orphans is also important. Maternal orphans may be *de facto* double orphans (missing father and mother both) due to the high proportion of female-headed households in the country (30 %). The ratio of paternal to maternal and double orphans is higher in earlier years of the epidemic because men tend to contract the disease first and die first. The proportion of children who are double orphans will grow as the epidemic deepens and more female partners die.

Orphan estimates do not include foster children (those with parents absent from the household but who are not dead), although non-resident parents may not provide support to the

	<b>Maternal and Double Number (%&lt;15)</b>	<b>Paternal Number (%&lt;15)</b>	<b>Total Number (% &lt;15)</b>
1990	152,391 (5.6%)	228,587 (8.4%)	380,978 (14.0%)
1995	189,313 (6.2%)	283,970 (9.3%)	473,283 (15.5%)
2000	189,450 (5.9%)	231,550 (7.3%)	421,000 (13.2%)
2005	178,938 (5.5%)	178,938 (5.5%)	357,856 (11.0%)
2010	170,807 (5.1%)	139,751 (4.2%)	310,558 ( 9.3%)

children's households. They also do not include children living in female-headed households unless the father is dead. However, both are important additional indicators of childhood vulnerability. In order to talk about orphans, we need to address the following categories of vulnerable children:

1. ***Children in Female-headed Households.*** According to EMMUS II data, 25.3 % of children under 15 in Haiti are living with their mothers only. In addition to the 4.5 % of orphans who have lost their father (paternal orphans), 20.8 % have a father still living but not resident. In general, female-headed households tend to be poorer and have less access to economic resources.
2. ***Fostered Children.*** According to the EMMUS II, 15.5 % of all Haitian children are fostered (living in households without either biological parent), and 12.7 % of all Haitian children are fostered even though both parents are still alive.
3. ***HIV-Positive Children.*** An estimated 20,000 (0.7%) Haitian children under 15 years will be carrying the virus by 2000. Orphan estimates do not include HIV positive children, who can be a substantial burden of care for families, communities, health facilities and health and social workers. In addition, these infant and child deaths will contribute to the anticipated decline in Haitian life expectancy to 54.4 years by 2010. Reductions in life expectancy do not mean, of course, that HIV negative adults will live shorter lives, but on the average, when additional child and adult deaths from AIDS are included, that life expectancy for Haiti as a whole is reduced.

4. ***Children Living in Families with HIV/AIDS.*** If we assume that children are distributed relatively evenly among Haitian households with HIV positive adult members, then 7.7% of children under 15 in the country, or 250,000 orphans and non-orphans are living in families affected by HIV/AIDS. These children will help care for sick adults, may contract TB (a particular concern, given the low level of immunizations), and particularly female children will be forced to drop out of school to provide care or replace the labor of sick and dying adults. In addition to these deprivations, these children suffer the psychological trauma of watching a parent die. Children will continue to feel the effects of this trauma throughout adolescence and into adulthood. The number of orphans will overlap with the number of children living in families with HIV/AIDS because some orphans will not have infected caregivers.
  
5. ***Other Vulnerable Children.*** It is widely accepted that children orphaned by AIDS and other causes do not constitute the only group of vulnerable children in Haiti, and that through their life cycle, children may move in and out of various categories of vulnerability as their life circumstances change. The following are estimates of children in various categories of vulnerability:
  - a. ***Street Children.*** The number of Haitian street children is estimated in several studies to be 10,000. A 1999 census in Port-au-Prince, Jacmel and Cap Haitien estimates that the street children population of these three cities is between 6,430 and 8,030 (Bernier & Ponticq, 1999). High proportions of street children were reportedly engaged in casual and commercial sex and used drugs. Separate, formal estimates of children who are sexually exploited and neglected are not available, but the overlap with the street children population is probably high, and may grow as the number of orphans increases and adult supervision declines. Anecdotal evidence indicates that the extent of child abuse and rape is increasing over what was already a sizeable base.
  
  - b. ***Child Laborers/Restavek.*** An estimated 250,000 young domestic workers called *restavek* are identified as the largest group of at-risk child laborers in Haiti. They are currently being studied in research co-sponsored by SCF/UK, UNICEF, and ILO. Preliminary information indicates that they have semi-slavery status, many are physically and emotionally abused, and few have the opportunity for education.
  
  - c. ***Disabled Children.*** In 1998, MSPP estimated that 525,000 (7%) of all Haitians are disabled, almost half of whom are blind. If the age distribution of the disabled population is similar to that of all Haitians, then roughly half are under 15 years old (260,000).
  
  - d. ***Children in Institutions.*** Haitians and expatriate child care professionals are careful to make it clear that Haitian orphanages and children's homes are not orphanages in the North American sense, but instead shelters for vulnerable

children, often housing children whose parent(s) are poor as well as those who are abandoned, neglected or abused by family guardians. Neither the number of institutions nor the number of children in institutions is officially known, but *Chambre de l'Enfance Nécessiteuse Haïtienne* (CENH) indicated that it has received requests for assistance from nearly 200 orphanages around the country for more than 200,000 children. Although not all are orphans, many are vulnerable or originate in vulnerable families that hoped to increase their children's opportunities by sending them to orphanages.

The CENH figures seem high when compared to Schwartz's (1999) count of five rural and three urban orphanages in the Northwest Province and Northern Artibonite, with a total of 376 children. Catholic Relief Service provides assistance to 120 orphanages with 9,000 children in the West, South, Southeast Provinces and Grand Anse, but these include only orphanages that meet their criteria. They estimate receiving 10 requests per week for assistance from additional orphanages and children's homes, but some of these are repeat requests.

## **B. Health and Social Status Indicators: Underlying Vulnerabilities**

Children in Haiti have been placed at higher risk over the past decade by declining economic circumstances. Roughly 70% of Haitian households are below the poverty line, a proportion that has increased in the last five years. It has been established that economic conditions like these can increase the spread of HIV. While many are hoping that HIV prevalence is leveling if not declining, a resurgence of seroprevalence in HIV affected groups has occurred where prevention and care efforts were not sustained.

From the perspective of care, children in Haiti, whether HIV/AIDS affected or not, are very vulnerable to other diseases as measured by infant and child mortality and morbidity statistics, and do not have ready access to basic health services. A history of extremely high rates of maternal mortality mean that vulnerability to orphanhood in Haiti was very high even before the epidemic began. In addition, the health and nutrition of HIV negative children and children who are not orphaned are likely to be stressed as families assume the responsibility of care for additional orphans. Although Haiti-specific data were not available at the time of this assessment, many studies of HIV/AIDS in Sub-Saharan Africa have noted that increasing numbers of orphaned children, and increasing mother to child transmission of HIV, are eroding reductions in infant and child mortality over the last two decades. Specific studies of the health of orphans have shown that these children are disadvantaged in terms of access to health care, immunization, and nutrition, even after they reach the age of 5 years.

As similar conditions and consequences now prevail in Haiti, it is likely that similar trends will hold true. Without widespread responses from health and education systems – including radical revision in policies affecting payment for and access to services – conditions could worsen drastically. It will be essential, for example, to eliminate all barriers to immunizations and other basic health services so that all children including

those affected by HIV/AIDS will have maximum protection provided by the health care system. Health professionals may need information on vaccination protocols for HIV-positive children, and programs should ensure that children lacking parents or primary caregivers also receive the full round of immunizations.

Many of the lessons learned from sub-Saharan Africa, such as from Uganda, are transferable to Haiti's situation, and should be studied carefully by policy makers.

### C. Total Vulnerable Children in Haiti

The total number of vulnerable children in Haiti is estimated at 1,210,000, or between 20 and 25% of the under 15 population. This estimate includes orphans not living at home (200,000), HIV-positive children (20,000), 70% of children in female-headed households and foster children who are in impoverished families (700,000 and 280,000 respectively), and 10,000 street children. Children in HIV affected households, children in institutions, disabled children and children in conflict with the law are presumed to be included in other categories of vulnerability. Orphans not in families may be assumed to be in institutions or in foster care of unrelated adults. The 250,000 *restaveks* in Haiti estimated by UNICEF's Plan of Action for Children's and Women's Rights are assumed to be included among fostered children. This estimate is debatable, of course, and should be subject to further study, but it provides a rough idea of scale of vulnerability of children in Haiti.

### D. Distribution by Geographic Area

Estimates of orphans or vulnerable children by province are not available from EMMUS II, but will be obtainable from special tabulations of the 2000 EMMUS III. If this distribution is similar to the distribution of HIV infected individuals (Section II of this report), then the provinces with the largest proportion of children under 15 who are orphans or living in HIV/AIDS affected families will

<b>Especially Vulnerable Children in Haiti</b>	
<b>Total</b> , without overlap --	1,210,000
Total = Orphans not in families (includes institutional and street populations), HIV positive kids, 70% of fostered children and 70% in female-headed households (70% = percent in poverty); and street children	
<b>Orphans</b> – Total:	320,000 - 420,000
Not in families –	200,000
<b>HIV positive children</b> –	20,000
<b>Children in female-headed households</b> –	1 million x 70% poor = 700,000
<b>Fostered children</b>	400,000 x 70% poor = 280,000
<b>Street children</b> --	10,000
Children in HIV/AIDS affected households, disabled children and children in conflict with the law are assumed to be included in one of the other categories listed below:	
<b>Children living in families with HIV/AIDS</b>	230,000
<b>Institutions</b> (orphanages, children's homes, hospital wards, poor houses) –	220,000
<b>Disabled</b> –	260,000
<b>Restaveks</b> –	250,000

<b>Statistics on Child Survival in Haiti</b>	
Infant Mortality Rate	74/1000
Under 5 Mortality Rate	137/1000
Moderate/severe stunting	32% of < 5 yrs.
Moderate/severe underweight	8% of < 5yrs
Children <1 year fully vaccinated	18.7%
Access to a health facility	50%
Safe water	25-30%
Safe sanitation	28%
Maternal mortality	600/100,000
Net Primary enrollment rate, ages 6-12	66%
Adult literacy (male/female)	44%
Percent urban	20%
GDP per capita	\$250
Percent below poverty line	70%

be in the Center, Northwest, West and North Provinces. The proportion of orphaned children is also likely to be higher in urban areas if it follows the distribution of seroprevalence. However, if children are sent to live in rural areas following the death of parents in cities, the opposite may be true. According to UNICEF's top program managers, it is difficult to target programs geographically because definitive, current data by province is not generally available and will not be until EMMUS III is analyzed.

The distribution of other vulnerable children may be slightly different than that of orphaned or fostered children reported in the EMMUS, because children in *restavek* arrangements may be slightly more concentrated around particular urban areas, like street children. Targeting for children in orphanages will follow the location of orphanages, which are said to be growing quickly in urban centers with increased AIDS-related deaths.

## **E. Registrations of Orphans and Vulnerable Children**

Orphan registrations have not been undertaken extensively by Haitian communities, although some 130,000 children have been registered through NGO child sponsorship programs. While registrations may be a good exercise for local NGOs or health volunteers, centrally directed enumeration exercises have several drawbacks. Based on the experience in other countries, central enumeration of children can be expensive, produce unreliable numbers, and raise expectations of families for assistance.

## **F. Studies of Children's Needs**

Research studies of children in need in Haiti are few. UNICEF, ILO and SCF/UK have collaborated on two research studies. The first study, of street children, was completed recently (see above, "Street Children"), and the second, of *restaveks*, is now underway.

Only two research studies in Haiti specifically discuss the situation of children and families affected by HIV/AIDS. The first, a qualitative piece of research entitled "SIDA Famille Soci t : Recherche Qualitative sur les Mechanisms de Soutien dans les Familles et les Communaut s en Haiti", was conducted by Institut Haitien de L'Enfance in 1995 in four sites in Haiti: Grand Goave (West), Les Cayes and Fond de Negres (South), and Port de Paix (Northwest). The study found that AIDS illness and death resulted in social isolation of the entire family, not just the sick person. The communities studied did not feel responsible for the care of AIDS affected families, but thought care should be the responsibility of outside organizations. Orphans suffered the same stigma as their parents. While most orphans were taken in by relatives, some were left on their own to cope.

The second study, "The Most Vulnerable: A Needs Assessment and Evaluation of Institutions Serving Vulnerable Populations in the Northwest Province and Northern Artibonite" (Schwartz, 1999), was prepared in 1999 for CARE/Haiti. The focus of the study is on identifying vulnerable groups, and the author notes that "the people who are

not included in any kind of food support or development activity are orphans, the elderly, HIV/AIDS affected people, handicapped or other more vulnerable groups.”

According to Schwartz, in Haiti, orphaned children are often cared for by their grandparents or other relatives when their parents die, in part because children are relied on for daily household chores. A child is seen as an economic asset rather than a liability.

In the study area, formal HIV/AIDS programming, even at the institutional level, was weak or non-existent, so communities were assuming the necessary tasks of care, both for HIV/AIDS affected adults and their families.

**Common Problems of Orphans and Their Families Found in Country Surveys in Sub-Saharan Africa**

- \_Large numbers of orphans per family
- \_Increased poverty
- \_Lower nutritional status in fostering households for all children
- \_Increase labor demands on children
- \_Reduced access to education
- \_Harsh treatment and abuse from step/foster parents
- \_Less attention to sickness in orphans
- \_Segregation and isolation at meal times
- \_Loss of property and inheritance
- \_Forced early marriage of female orphans
- \_Higher mortality
- \_Abandonment
- \_Lack of love, attention, affection
- \_Grief for parents, separated siblings
- \_Defilement of female orphans

Although studies of HIV/AIDS affected families and children in Haiti are few, the countless other studies of the situation of orphans and their caregivers that have emerged from Sub Saharan Africa over the past 10 years can give us some idea of the increasing difficulties facing orphans. While the surveys generally find that orphans are still being absorbed by the extended family, many children and households suffer greatly from poverty and hunger, going without food for extended periods. The family and community are able to provide sufficient support to orphans so that few end up on the streets, as evidenced by the low number of street children in Haiti, but the needs of these children are far from adequately met. Young teenage girls often take up commercial sex work to buy clothing and meet other needs. Caregivers often reported difficulties in paying school costs.

**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 HIV/AIDS-related stigma and discrimination
- \_Access to health, education, social services and safety nets

Most of the children were comforted by not being split from their brothers and sisters, but splitting siblings among foster parents becomes more common as more caregivers die. Caregivers were predominantly women, many of whom are elderly and poor. Children and caregivers both experienced reduced access to resources in health, education, and social welfare.

These studies show that the needs of orphans, just like other children, vary by their age and sex. Children who have been orphaned by AIDS have the same needs as children orphaned by other causes, although they may suffer additional discrimination and stigma. The needs of orphans are also the same as other children in poverty: for food, clothing, shelter, and schooling. In addition, orphans and neglected children often need psychosocial counseling and assistance to deal with the grief they feel over their parents' deaths and the mistreatment they may suffer at the hands of guardians.

Orphans' needs can vary by the type of orphan, that is, the needs of a child missing its mother are quite different from the needs of children missing their father or both parents. Death of the mother is more critical for children below the age of 5, while death of the father has a greater effect on the development opportunities of older children. A child missing both parents is generally the most vulnerable of all types of orphans.

<b>Key Vulnerabilities of Haitian Households</b>
_Households are large -- 30% of households have six or more members
_25% of families include foster children
_70% of households are below poverty line
_80% of households are rural with limited access to health, education and sanitation services
_40% of households are female-headed
_18% of mothers surveyed in EMMUS II suffer acute malnutrition
_Dependency ratios are high, 96 dependents to 100 productive adults

The mix of maternal, paternal and double orphans changes as the epidemic grows in a country. In Haiti, where a large proportion of women are supporting children on their own, the proportion of children who are “de facto” double orphans is likely to be higher than in other countries in the region. Even when a child's father is not dead, he often fails to provide support.

Parental death status will also be a predictor of which family member will be the child's guardian, or if the child has any guardian at all. Children staying with their grandparents, especially an elderly grandmother, are often very vulnerable. Stepchildren are characteristically treated more harshly than biological children. Children who are taking care of children are even more vulnerable, and child headed households are becoming more common as a greater number of potential guardians succumb to AIDS or other causes of death.

The following lessons learned and trends emerging in child protection due to the HIV/AIDS epidemic were highlighted by a recent study of orphans in Swaziland:

1. Siblings should be kept together
2. Children need to stay in their own homes and communities for continuity and security
3. Many children are responsible for their own survival and that of their siblings
4. Caregivers are often elderly women
5. Income generating projects are needed
6. Psychosocial counseling should be continuous
7. HIV+ parents should know their status to prepare their families for death

8. Monitoring system to prevent abuse needed
9. Work through traditional structures
10. Families provide most of the aid
11. Support to families is self identified
12. Support to families is urban biased
13. Coordination and cooperation of support systems is not strong
14. Leadership and policy is urgently needed
15. Situation is tenuous because support systems are fragile
16. Research is needed on the children, their caregivers and systems of community support

## **G. Situation of Caregivers in Haiti**

The situation of families and caregivers in Haiti merits attention. EMMUS II statistics show that Haitian households average five members, but over 30% of non-metropolitan households have six or more members. Overall, 25% of Haitian families include fostered children whose biological parents are not resident. This proportion is slightly higher in urban areas. According to Schwartz, the practice of using children as domestic workers is widespread among all types of families – urban, rural, rich, and poor – which helps to explain the high proportion of families with unrelated children.

Deprivation in Haiti seems to be fairly ubiquitous. Poverty studies show that 70% of Haitian households are below the poverty line. A recent World Bank study indicates that female-headed and landless households are among the most vulnerable of Haiti's poor. Female-headed or managed households comprise 40% of all households in Haiti. The World Bank study indicates that “endemic poverty continues to fuel male dominated migration”. These households are generally poorer and more vulnerable than male headed households, but are those most likely to be providing care for HIV/AIDS affected and infected adults and children.

The largest proportion of Haitian households (80%) are rural, 96% of which lack electricity, running water, and toilets. Poor sanitary conditions for children reflect themselves in large numbers of cases of diarrhea and other gastrointestinal illnesses. Malnutrition is widespread among adults as well as children. Some 18% of mothers included in the EMMUS II sample suffered from acute malnutrition, 12% of urban women and 21% of women in rural areas.

Anecdotal reports indicate that many orphans in Haiti are cared for by their grandparents, aunts and uncles on the mother's side. Persons over age 60 comprise 5.9% of the Haitian population. While the overall ratio of men to women is 98 to 100 in Haiti, in age groups over 60, the ratio of males to females is 86 to 100. The dependency ratio was estimated to be 76 in 1999, meaning that 76 persons (children, the elderly, the disabled) are supported by 100 economically active individuals. For comparison, this is almost twice the ratio in France.

## IV. THE STATUS OF THE RESPONSE

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### A. Family and Community Response

National estimates show that more than half of all estimated orphans and large numbers of other vulnerable children are still cared for in families of some configuration. Relatively small proportions of all vulnerable children are outside of some type of family setting. If there are now 1.2 million vulnerable children in Haiti, slightly more than one sixth are in institutions or living on the streets. However, some institutionalized children and street children do not live in institutions full time. In addition to the evidence from national estimates, a local, more detailed study sponsored by Plan International (Plan) in two provinces support this conclusion. Given the disadvantaged economic and health care situation of Haiti, it seems likely that care for orphans will continue to come largely from extended families and communities.

While this is true, not all children in families are thriving. Some *restaveks* for example, are “fostered” children who suffer from a variety of abuses and whose basic human rights are not respected. Other indicators signal that additional support is needed if families are to provide for children’s basic needs and rights. The high level of malnutrition, low school attendance, low immunization rates, and high infant and child mortality signal problems for all families that must be addressed if family care for a large majority of children in Haiti is to be improved. Community-based monitoring systems may also be needed to assist families with social, economic or psychosocial difficulties.

Conversations with NGOs and government workers indicate that constraints on the supportive capacity of families and communities are several:

1. Poverty within families;
2. Lack of organization and skills,
3. Fear of HIV and stigma experienced by HIV/AIDS-affected families;
4. Lack of income or surplus to share between families.

NGOs working with community programs in Haiti indicated that families are willing to maintain HIV/AIDS patients and their children at home if they received training, assistance with organization, contact, and psychosocial assistance. CARE recently ran a successful pilot program in Grand Anse that demonstrates how open community discussion and planning can reduce stigma toward HIV/AIDS-affected families and children and motivate development of local responses. Plan International and Catholic Relief Services (CRS) are finding similar responses in their community-based HIV/AIDS programming. If concerted effort is made to diffuse these responses to a larger number of communities, the sustained development benefits resulting can contribute to poverty reduction.

This type of result was found in recent national surveys in South Africa, Zambia and Malawi, which all have increasing numbers of orphans due to the HIV/AIDS epidemic. These studies indicate that families are willing to accept and care for children if their resources are sufficient, and will undertake community development and income generating projects to increase their resource base. Anecdotal evidence suggests that this feeling is shared in Haiti. Cost estimates also indicate that it is far cheaper to support care in the home than to incur either the cost of constructing institutions or curbing social problems brought on by children dislocated by loss of parents and guardians

Haitian households affected by HIV/AIDS experience special difficulties in accessing already scarce health and education resources. In addition, experienced NGO experts say caregivers and children experience stigma and discrimination if their parents or partners had died of AIDS, their caregivers were infected, or they

were living in families affected by HIV/AIDS. While the practice of property grabbing from widows common in Sub Saharan African countries is not common in Haiti, land owners who lack legal title to their property are generally victimized in land transactions.

Findings of recent surveys in Malawi, with a similar income and development profile to Haiti, have found that many families were stressed by the addition of foster children. In many communities, family members were unwilling to absorb any additional children because of economic and psychological stress. However, once the villagers met their needs for psychosocial counseling, and received support in the development of income generating projects and increased agricultural productivity, they reassumed their traditional responsibility of caring for orphaned children within the extended family.

This research suggests that the extent of community and family support programs -- psychosocial, organizational and economic -- can determine how serious a social problem Haiti will face in the coming years in managing the growing numbers of orphans in the country. As the number of orphans rises, families will presumably exhaust their capacity to absorb additional children with their current range of technologies and resources.

<p><b>Support for Community Responses in Haiti</b></p> <p><b>Positive Indications of Support</b></p> <ul style="list-style-type: none"> <li>_Low numbers of street children</li> <li>_Active and expanding NGO and church based activities</li> <li>_Recognition by many partners of the limits of institutional approaches</li> <li>_Ministry of Social Affairs support for CARE activities in Grand Anse</li> </ul> <p><b>Constraints on Community Support</b></p> <ul style="list-style-type: none"> <li>_Poverty</li> <li>_Many families with HIV/AIDS are stigmatized</li> <li>_Government approaches to community-based social welfare have not been developed</li> <li>_Potential safety nets for poor families and children, including food security programs, are largely targeted at children in institutions and schools</li> <li>_Lack of government or NGO extension workers to promote organization of community responses</li> <li>_All partners must be involved so resources are maximized in a strategy of protection</li> <li>_Local leaders, who could identify vulnerable children and families, need to be prepared for this task</li> </ul>
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Accelerated introduction of support programs through a variety of agencies may be the key to determining the long run success of family and community response in Haiti. Through these programs, the skills and productivity of the community can be expanded so that diminishing numbers of adults can support greater numbers of children, a finding with substantial positive development implications for the country.

The report of proceedings from a 1999 National Forum aimed at increasing media awareness of HIV/AIDS in Haiti notes that weak support from existing health infrastructure aggravates attempts to strengthen national responses. The majority of organizations focused on HIV/AIDS are concentrating on prevention of HIV and STIs, and few on their treatment. Resources allocated to these organizations were reduced drastically over the last five years, and are currently at 10% of the level they were from 1990 to 1995. With such radical cuts in funding levels, it is not surprising that so few resources are dedicated to community-based development.

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| <p style="text-align: center;"><b>Sources of Support for Family and Community-based Care</b></p> <ul style="list-style-type: none"><li>_Developing government policy and strategic planning</li><li>_Individuals, families, children</li><li>_AIDS Service Organizations</li><li>_Church, health, AIDS, and women groups</li><li>_Province and local leaders</li><li>_Government outreach workers</li><li>_Teachers</li><li>_Child care institutions and orphanages</li><li>_AIDS-related youth clubs</li><li>_Traditional healers</li><li>_Private sector for large employers</li></ul> |
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Families and communities need support through NGOs, local leaders, churches, and government extension workers to competently shoulder the burden of care for PLWHAs and orphans. CARE's project in Grand Anse has demonstrated that even communities where initial response is very negative can be convinced of the importance and feasibility of community care and will undertake voluntary activities to promote it.

Communities in Haiti are constrained by a number of factors, the most important of which is poverty. A second constraint is stigmatization of families affected by HIV/AIDS, which provides opportunists with justification for exploitation and other community members with justification for withholding assistance. Many who might also help believe that the government should provide assistance, although there are many important reasons why this is an unlikely source of help for many families.

## **B. Institutionalized and Group Care**

The lack of support or safety nets for families who want to maintain children at home makes orphanages more attractive. According to a number of observers, many children in orphanages are not orphans and are sent by their families so they can receive food, medical care and schooling. The school-feeding program helps some families maintain their children at home, but these are not likely to be the most vulnerable families or those with the most vulnerable children because they can still afford to send their children to school. According to the Ministry of Social Affairs, some foster care grants are given, but other observers interviewed did not know of their existence. Schwartz notes that

orphans, the elderly, HIV/AIDS affected people, and the disabled have not been traditionally targeted by food or development activities.

The lack of support for families, limited development of community-based programs, and increasing reliance on institutions makes the environment for care in Haiti very different from that found in other countries with severe HIV/AIDS epidemics. In Haiti, it is estimated that 200,000 or more children (7 to 8 % of all vulnerable children) are in orphanages or institutionalized group settings. This is a substantially higher proportion of orphaned children in institutionalized settings than is found in most other countries similarly effected by the epidemic. In the long run, the institutional approach has serious negative implications:

1. Orphanages are difficult and expensive to regulate and monitor properly; particularly in the absence of a skilled cadre of social welfare officers;
2. Orphanages encourage increased dependency on external sources of support with potentially disastrous consequences when they are withdrawn;
3. Orphanages discourage efforts to maintain and integrate children into families through community development programs with poverty reduction components;
4. Children have difficulties adjusting to social life when they leave institutions;
5. Children often lose their land, property, and contact with their families and traditions when they are institutionalized.

While a system based on orphanages often discourages the development of family and community- based care as described in the preceding section, in Haiti the system seems to provide a crucial safety net for children from impoverished families and communities and keeps many children from becoming street children. Orphanages could serve as a base for development of community care and awareness raising about HIV/AIDS, families, and children. One orphanage has demonstrated how good care can be provided for HIV positive children and also pioneered community outreach programs to encourage community care and stability of AIDS affected families. Haiti has relatively few street children compared to other HIV/AIDS-affected countries, possibly because currently estimated orphanage capacity is large, equal to half of estimated number of orphaned children.

Several safety net programs in Haiti encouraged the growth of institutions and currently function to support them. One example is the food security program in Haiti, which is funded by several donors and administered by a group of cooperating sponsors (CARE, Bureau National de Developpement (BND), and CRS). This support is particularly important to a large majority of orphanages, but is also targeted to maternal and child health care institutions.

Another line of support for childcare institutions in Haiti are child sponsorship programs, some of which include children in orphanages. In his study of vulnerable populations in the Northwest Province and Artibonite, Schwartz (1999) notes that World Vision and Compassion International have 58,500 sponsors for children in Haiti. According to

Schwartz, CAM has 10,000 child sponsors, and the Haiti Baptist Mission has 57,800. Other child sponsorships include the Tear Fund, the Lebens Mission in Goanaives, and a church sponsored mission in Port-de-Paix. The proportion of sponsored children in orphanages or children’s homes was not indicated in the study.

There are two initiatives underway to support changes in the institutional system. Chambre de l’Enfance Nécessiteuse Haïtienne (CENH) is a new organization supported by USAID to improve quality and management of Haiti’s orphanages. CENH registers orphanages according to established criteria, and improves quality of care by providing management training and building accountability. CENH also encourages community building through training for institution boards of directors, and encourages volunteerism to improve links to the surrounding community.

CENH shows the following distribution of institutions that have requested its assistance:

<b>Province</b>	<b>Number of Requests Registered</b>
Ouest	106
Artibonite	41
Sud	8
Sud-Est	10
Centre	6
Nord	15
Grand Anse	4
Nord-Est	0
Nord-Ouest	1
<b>Total</b>	<b>191</b>

CENH has not been able to review or visit all of these facilities, but estimates that they serve at least 200,000 children. Le Ministère des Affaires Sociales- Bien Etre Sociale licenses and regulates state-recognized orphanages, but it is likely that many of the institutions listed above, particularly the newer ones or those without international sponsorship, are not in conformity with regulations. In addition, CENH indicates that services provided by many institutions are weak, and many struggle to supply food, education and other necessities to the children they house.

The second initiative involves using the orphanage as a base for developing family-based responses in the surrounding community. This is one of the most significant contributions of Maison L’Arc-en-Ciel, an orphanage in Port-au-Prince that is one of two in Haiti to openly accept HIV positive children. Its professionals have developed a system of care for HIV positive children that focuses on early treatment of opportunistic infections. Maison L’Arc en Ciel is also supporting HIV/AIDS-affected families in nearby neighborhoods with counseling, training, and food aid. It regularly hosts visits by school children and community members to increase awareness of children with HIV/AIDS and combat stigma. The program grew out of the Maison’s difficulties in obtaining care for the HIV positive children or those with AIDS in its care. Even now, only one hospital will care for the orphanage’s HIV positive children. The facility

managers claim that adult HIV/AIDS patients also have trouble obtaining care in Port-au-Prince, an observation that seems supported by other observers.

### **C. Health Facilities and Home Care**

Hospital and home- based care for lower income HIV/AIDS patients is virtually unavailable in Haiti unless patients receive services through special studies such as those conducted at the Gheskio Center or associated clinics in Port-au-Prince. Patients who are not in such studies or circumstances must pay for their own drugs with the exception of drugs for TB, which are free of charge. While treatments for STIs are supposed to be provided free of charge, the drugs are still not widely available.

Despite the existence of the epidemic for two decades in Haiti, systems of care are only now under development. Gheskio has just completed a study which tested a medical home care model under World Bank auspices, but their program recommendations have not yet been released. As described in an interview with Gheskio staff, the model requires regular home visits and medical treatment that may not be feasible for the health care system on a national level or afforded by the patient on a personal level.

The diagnosis and treatment of TB and HIV/AIDS remain low priorities. A study by Schwartz in Northwest and Artibonite Provinces found that medical facilities had no protocol or drugs for dealing with HIV/AIDS or TB, supporting the findings of a 1998 MSPP review of care in the region. Reportedly, physicians still do not tell their patients or families their diagnosis when they test positive for HIV.

CARE found that similar conditions prevailed in its six Grand Anse study sites. Reports on the status of care in other provinces were not available to the consultants, but it is probably a fair assumption that conditions are the same nationwide.

#### **AIDS/STI Care in Haiti**

- \_Care from hospitals for PLWHAs is virtually unavailable in Haiti
- \_Many hospitals are not equipped to provide care for HIV positive children
- \_TB care may also be weak
- \_Hospital-home care model just tested; may not be feasible for most institutions and PLWHAs in Haiti
- \_Drugs for relief of opportunistic infections may be too expensive for most Haitians
- \_Most doctors do not tell HIV positive patients of their diagnosis

### **D. Government Response/UN Assistance**

*Government Response.* Haiti's current National Strategic Plan for HIV/AIDS Prevention and Control, covering the period 1996 to 2000, recognizes family and community care as a basic principle of HIV/AIDS care in the country. The second objective of the Plan is to support family and community care for PLWHAs, and to that end, to develop systems which provide nutritional, economic and social support for infected adults and their families. One of the goals for the current planning period was to develop a guide for home care, medicines, home visits, psychosocial care, provision of food and planning support for orphans.

*Social Affairs.* According to the Minister of Social Affairs, the government is interested in promoting the development of community-based care in all areas of the country for adults and children living with HIV/AIDS and for children who are orphaned or left vulnerable by HIV/AIDS. It proposes to do so by providing office space and a government social welfare officer to work for CARE's project in Grand Anse to develop family and community care in six provinces. The Minister would like to provide the same support for similar projects in every province of Haiti, and would provide office space and a social worker to work with collaborating NGOs in each. However, UNICEF has estimated that there was only one trained social welfare officer per province.

The Ministry's mission is to provide care to all vulnerable children and women in Haiti. To that end, it is cooperating in the development of projects for commercial sex workers and street children in every city. The Ministry also has legal authority over children's homes, and is responsible for their licensing and regulation. In addition, the Ministry has endorsed the UNICEF, ILO and SCF/UK on research on street children and *restavek*, and is working with UNICEF and other partners on revisions to children's law, including revisions of old adoption and fostering statutes. The Minister indicated that government grants are available to help support foster children and children in institutions.

<p><b>Government Activities to Promote the Welfare of HIV/AIDS Affected Children and Families in Haiti</b></p> <p><b>Health</b></p> <ul style="list-style-type: none"> <li>_National HIV/AIDS Plan endorses community care as a core principle of HIV/AIDS prevention and control in Haiti</li> <li>_Guide for home care is part of the 1996-2000 plan</li> <li>_New national strategic plan under development in cooperation with UNAIDS</li> <li>_Home care model tested under World Bank project</li> </ul> <p><b>Social Affairs</b></p> <ul style="list-style-type: none"> <li>_Collaborating with CARE on development of family and community care; wants to expand program to all provinces</li> <li>_Wants to expand programs for street children and commercial sex workers to all major cities</li> <li>_Endorsed UNICEF/ILO/SCF-UK studies of street children and <i>restavek</i></li> <li>_Regulates orphanages</li> <li>_Revising children's law, including adoption and fostering statutes in collaboration with UNICEF project</li> <li>_Cooperating in a review of the child justice system and children in conflict with the law</li> </ul>
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*UN Assistance.* UNDP has sponsored research into community responses to HIV/AIDS. In addition, UNAIDS is now mounting a national situation analysis of HIV/AIDS prevention and care, to be used as input to the preparation of a new national strategic plan. The Government of Haiti/UNICEF's program for the current period emphasizes several activities:

1. Research and program development for street children and *restavek*;
2. Revision and codification of child law;
3. Development of a humane juvenile justice system, including the organization of children's courts in five cities.

In addition, UNICEF is collaborating with the Ministry of Health and the Gheskio Center on the study of AZT interventions in reducing mother to child HIV transmission. The report to the International Committee on the Rights of the Child, currently under preparation, describes Haiti's implementation of the Convention on the Rights of the Child, since its ratification in 1994. According to UNICEF's current Plan of Action for Children and Women's Rights the problem seems to be not in developing new laws, but in enforcing existing laws. The report to the International Committee on the Rights of the Child promises to be a document rich in current information on the efforts in Haiti to guarantee child rights.

## **E. Voluntary and Community-Based Responses by NGOs**

The private voluntary sector, which includes agencies that are not part of the government or commercial private sector such as charitable NGOs and churches, provides approximately 40% of all health care in Haiti. In addition, as we have seen above, they also implement the majority of programs for family and community-based HIV/AIDS prevention and care, orphanages, and food security programs. Most HIV/AIDS-related NGOs are providing public education and awareness raising, and services to PLWHAs. NGO orphan support programs that exist have emerged, for the most part, as offshoots of home care and visiting programs for the sick.

NGO HIV/AIDS activities have concentrated on the prevention of HIV transmission, stressing community education programs for young people and high-risk groups. For example, Fondation pour la Santé Reproductrice et Education Familiale (FOSREF) has pioneered youth peer education programs, street theatre, education, and programs for street children, and is now planning to implement a program to look at the interaction of teen pregnancy and the entry of young women into commercial sex work. The project aims at complete reintegration of these young women by working with them to develop life alternatives and work. Currently active in six provinces, FOSREF is interested in conducting qualitative, participatory research to determine how to best identify vulnerable children, help them and their families, and integrate children into peer groups, prevention activities, and basic services.

Promoteurs de l'Objectif ZéroSIDA (POZ), is a Port-au-Prince based HIV/AIDS information and coordinating center that promotes NGO networking and provides technical assistance in project design, communication, behavior change, and advocacy in addition to a broad media awareness campaign, a hot line, community mobilization activities, and support for voluntary counseling and testing. Currently coordinating an NGO group for advocacy, it is interested in expanding its coordinating role to develop a national strategy for families and communities affected by HIV/AIDS.

Although CARE's programming in family and community care for HIV/AIDS affected persons is best known because of the release of its recent study in Grand Anse, "Recherche Participative Soutien aux Personnes Atteintes de VIH/SIDA et à leur Famille," both CARE and Plan have programs underway to develop family and community-based programming in provinces where they are active. CARE also

administers food relief in Northwest, Northeast, and Artibonite provinces. Plan serves Northeast, West and Southeast provinces. Plan is starting a new program to provide peer education for in and out of school youth, community education and discussion of HIV/AIDS prevention strategies, and support groups for HIV positive children, working with POZ.

SCF/UK works in community-based development in the Central Plateau and Western provinces. As part of a national HIV/AIDS prevention project begun several years ago, it organized a group of NGOs in the Central Plateau for prevention and care that were active until recently. SCF/UK has been working to develop community-based women's organizations, a project that includes health, credit, and income generating activities, and is now expanding that project.

CRS administers the food security program in half of the country (West, Port-au-Prince, South, Southeast and Grand Anse). As part of this program, it organizes educational programming for managers of the child care facilities that receive food. In addition, it is developing an HIV/AIDS prevention and care program that includes community education for stigma reduction and developing community-based responses. CRS is interested in developing programs in family and community care for orphanage and facility managers and also in providing community education and training through its regular HIV/AIDS program.

CARE, Plan and SCF/UK have indicated that they would be interested in collaborating to carry out provincial level focus group research to investigate family and community coping strategies and also to explore possibilities for planning new services.

## **F. National NGO Networks**

As indicated above, NGOs in Haiti divide their work by province. While this seems to have originated in administration of the food security program, it provides a convenient means of organizing other initiatives. Many of the NGOs described above also participate in the NGO network organized by POZ to increase media awareness. According to the UNICEF program manager interviewed, while NGOs concerned with child protection have always tried to coordinate their activities, an earlier network of NGOs working with children in special circumstances dissolved more than three years ago.

In addition to the NGOs already described, a major network of NGO health care facilities responsible for providing 40% of child survival and reproductive health services in Haiti is undertaking a new USAID- funded project in Haiti called HS2004. In addition to providing direct care in reproductive health and child survival, this group provides much by way of community and family education, including HIV/AIDS and STI prevention and care. It runs three radio projects: a distance learning program for community health workers associated with member facilities, public education spots, and a soap opera.

## G. Policy Development

A 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.

Haiti does not have a specific national orphan policy. It is working with UNICEF to develop a Children's Statute such as that found in Uganda. However, Haiti's parliament ratified the Convention on the Rights of the Child in 1994 and is also a signatory to the Convention for the Elimination of All Forms of Discrimination Against Women. However, it is generally observed that much has to be done to establish women's and children's rights as a norm in Haitian culture.

### 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

## I. Social Safety Nets and Poverty Reduction

Safety nets for families and children affected by HIV/AIDS in Haiti are few. Indeed, these may be among the most vulnerable populations in Haiti because they are not

targeted by assistance programs. As noted above, food security programs, orphanages and child sponsorships provide some protection.

Official government safety nets for families and children affected by HIV/AIDS seem, compared to other heavily HIV/AIDS-affected countries, are lacking. In many high prevalence countries there are several types of government income transfers: fostering and adoption care grants for children, old age pensions for caregivers, and disability grants for PLWHA. There are also official government policies and programs to encourage development of family and community-based care, and national coordinating bodies spearheaded by government to oversee their implementation. Several countries have implemented free universal primary education and early childhood development centers to ensure that children are fed and their psychosocial and physical development are monitored. In addition, many countries provide free access to primary health care for orphans, and provide free treatment for STIs and TB and HIV/ AIDS-related infections.

## V. CONCLUSIONS

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Health, education and income statistics indicate that a very large proportion of Haitian children are vulnerable, and about 25% may be classified as extremely vulnerable. The basic human rights of many children for health, education, and protection in Haiti are not adequately met. The HIV/AIDS epidemic is only one cause, aggravating underlying factors of poverty and lack of access to services. It is not only orphans who are vulnerable, but also large numbers of children in other living arrangements. Even if HIV prevalence were to level or decline, the number of adults and children who are already infected and will die within the next decade is staggering. Statistics also show that a large majority of Haitian adults who are the main caregivers of Haiti's vulnerable children are themselves vulnerable, not only to infection with HIV, but also through malnutrition and poverty.

Despite the decades-long existence of AIDS in Haiti, support for adults and children living with HIV/AIDS is not strong, either at the institutional level or at the family and community level. Services that are provided and planned are not well known. Present government policy is unclear on a number of issues. However, Ministries are developing plans and working on aligning law and its enforcement with the Convention on the Rights of the Child. Even those who have worked on HIV/AIDS for quite some time debate government policy on availability of drugs or its current thinking on provision of guidelines for hospital and community care.

Since the most effective ways to "prevent" orphans is to prevent adult deaths, the highest cost of failure to implement an effective HIV/AIDS prevention program may be borne by the next generation of children. The cost of failure to implement an effective multisectoral strategy will be enormous in other respects as well: loss of development gains and potential in all sectors, including loss of skilled personnel and infrastructure that cannot be maintained through long term losses of productivity; social unrest from children and youth who are unprotected, under-fed, under-educated, and poorly socialized; increase in morbidity and mortality due to HIV/AIDS will result in patient overload at hospitals and clinics prohibiting adequate response; and resurgence of other diseases, such as TB.

Several significant barriers remain to be addressed as this new strategic planning and policy development exercise gets underway. Denial is strong and PLWHAs experience high levels of stigma and discrimination. There remains a lack of sound protection measures for PLWHA to prevent stigma and discrimination and a lack of widespread accessible counseling and testing. The lack of participation on the part of NGOs, churches, the private sector and other partners in strategy development and implementation presents a real challenge. Widespread poverty throughout Haiti continues to exacerbate prevention and care efforts.

Although the impact of the epidemic will be felt well into the future, disaster is not inevitable. Although public health experts around the world have been humbled by their limited success in controlling the spread of HIV/AIDS, it is not impossible to reverse epidemic trends. In other countries increasing infection levels were reversed through deliberate public health strategies.

Haiti has a number of strengths for programming to contain the spread of HIV/AIDS in the country. The government is committed to establishing a broad, multisectoral HIV/AIDS policy and has started the process of its development. There is an increased widespread concern and awareness of the potential destructiveness of AIDS mortality and morbidity as well as the realization of the need to reallocate resources to care for children and families affected by the epidemic. A core of committed NGOs have organized as a national coordinating group. For the purposes of programming for children affected by HIV/AIDS, Haiti has a strong private health network. It also has several large NGOs, which together provide a variety of community development programs in all of Haiti's departments. There is a high level of awareness and concern for affected families and children. Many activities have been developed for HIV/AIDS prevention and control to ensure that sexually active adults in Haiti understand the threat of HIV and how to protect themselves. Further, there is a committed PLWHA group working on national information and education.

At present, family and community care appears to be viable for the majority of vulnerable children in Haiti, although orphanages and the food security program provide valuable safety nets for vulnerable children and families. Several important pieces of research on groups of especially vulnerable children are in place (street children and *restaveks*), but the larger group of children made vulnerable by the HIV/AIDS epidemic is not currently being addressed in a systematic manner.

## VI. RECOMMENDATIONS

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Based on the findings of this assessment, there are three major areas in which action steps should be taken: data gathering, promotion of community-based prevention and care, and development of appropriate policy. There are many organizations in Haiti ready to come together to promote family and community care for adults and children affected by HIV/AIDS. In addition, the government is now beginning an important strategic planning process that will require extensive input from NGOs and facilities managing and developing programs of care.

### *Data Gathering*

The gathering of the following data is essential in order to have a clear more comprehensive picture of the status of orphans and vulnerable children.

1. *Data on children and families.* Several important sources of data were identified during the consultation that will contribute a great deal to understanding and programming for vulnerable children in Haiti:
  - a. *Household Level* The national level analysis of household structure and living arrangements included in the general EMMUS III report will be useful. The resulting data could also be further analyzed to improve insights concerning the circumstances and distribution orphans and vulnerable children.
  - b. *Coping Strategies* An extensive study of communities surrounding member facilities should include data collection relevant to family and community coping with HIV/AIDS. A set of questions on coping strategies could be readily included in the basic questionnaire.
  - c. *Community based data.* NGOs should work together to formulate a common approach and timing for their studies on the level of response in the departments where they are working to be used in the national planning process described above.
  - d. *Qualitative data.* Partner NGOs should conduct a limited series of focus groups at the departmental level where the problems faced by AIDS affected individuals, families and children could be discussed. There is also the potential for separate group meetings with officials and facility directors.
2. *Data on communities*
  - a. Qualitative surveys should be conducted by NGOs in each department using focus groups to collect data on the status of family and community care and the best mechanisms to improve it.
  - b. A survey of community responses should be conducted.

3. *Data on facilities*
  - a. A survey of the number of orphanages and orphans by province is essential.
  - b. A survey of the existing facilities in each province is needed to document the state of HIV/AIDS care for adults and children. It would be helpful to have a definitive review by province of the availability of care or lack thereof for AIDS-affected adults and HIV positive children, including a review of access to hospital services, diagnosis, testing, treatment, and home care or community based care.
4. *New orphan estimates.* Existing estimates and projections of the number of orphans vary a great deal. New estimates should be generated for Haiti following the completion of the new seroprevalence survey.
5. *Geographic targeting and coverage.* The NGO planning group should review existing and forthcoming sets of data (EMMUS III, NGO community/departmental studies, new orphan estimates, street children and *restavek* studies) in order to establish strategies for geographic targeting of assistance.
6. *Targeting existing food security programs.* Data and strategies originating from the activities described above and from activities described at the end of the next section will be of considerable assistance to the review of food security programs by not only providing a better notion of children's vulnerability within families and communities, but also regularly updating information on the location and types of services provided by institutions.
7. *Regular monitoring of children's status.* Deterioration of children's conditions could be rapid with more AIDS deaths. All data on children and households will have to be updated periodically (every two to four years) because the situation of children and their caregivers is likely to change a great deal as the epidemic worsens. It is urgent that data collection and monitoring be given a higher priority in Haiti so that changes in children's conditions are known more quickly and action taken if needed for their protection.

### ***Community-based Prevention and Care***

Community-based prevention and care should form the cornerstone of any HIV/AIDS services plan in Haiti. While some essential elements of effective AIDS control have been put into place or are being expanded, more needs to be done to link prevention and care: prevention programs are more effective when linked with care; care will be a major development burden and must be properly funded; and children who are not absorbed will become a major social burden. Projections of the loss of human resources in key sectors -- for presentation to policy makers -- will begin to highlight requirements for mitigation of the human suffering caused by the epidemic. Implementation of the following could accelerate appropriate family and community responses:

1. Increased accessibility to HIV/AIDS testing and counseling. VCT is becoming more available but is still too costly for most Haitians;
2. Guidelines for care and management of HIV positive adults and children and those with AIDS are needed in the health care system;
3. Training for health care professionals in management of HIV in children is needed;
4. Guidelines for testing infants believed to be HIV-positive could reduce infant abandonment;
5. More emphasis on community based programming. This component is needed encourage home-based care of HIV/AIDS cases and family and community care for affected children;
6. Training for families caring for HIV-positive children and orphans will increase family and community willingness to care.

Several actions can be taken to promote community-based care and coordinate the process of its development as follows:

1. *NGO Planning Group.* An NGO group has been formed to coordinate HIV/AIDS prevention programs in Haiti. This same group could be organized to develop community-based care in Haiti, provide input into the UNAIDS national HIV/AIDS strategic planning process, and serve as a nucleus to develop a strategy for implementing community-based programming for PLWHAs, orphans, and other vulnerable children in Haiti.
  1. As a first step, this report should be distributed to all NGOs involved in community care, and convene a discussion group to review the findings;
  2. As data on the status of families and children is developed from a number of sources, the NGO group can review the findings;
  3. This group may wish to develop white papers on specific aspects of care (home care, development of community-based orphan and home care, testing and counseling, stigma reduction) to inform the national strategic planning process;
  4. NGOs in this group could expand the scope of the situation analysis to be prepared as part of the national strategic plan by conducting background investigation of the scope of care in rural areas through a participatory process;
  5. This group could hold a national meeting to report on its programming and findings of various surveys and data collection efforts conducted. This meeting should be coordinated with the process of MSPP and UNAIDS to develop a national HIV/AIDS strategic plan.
2. *Public Awareness Raising.* Stigma of HIV/AIDS affected adults, children and families is high in Haiti because the general public's exposure and knowledge is low. Education about HIV/AIDS and children affected by AIDS must be expanded to reduce stigma. NGO partners can play a role in developing public service

announcements and investigating the development of a radio soap opera dramatizing links between prevention and care, family issues, and childcare.

### ***Policy Development***

Coordinating and stimulating development of policy and response for families and children affected by HIV/AIDS is of particular importance. Issues of care, both for PLWHAs and their children, should be featured in the new National AIDS Plan and clearly linked with strategies for prevention. The following activities are recommended under the auspices of an NGO coordinating group:

1. *Education and training programs*
  - a. Community health workers and facility managers should be trained in how to care for HIV-positive children, and in the areas of family and community-based care.
  - b. Public awareness campaigns such as soap operas and public service announcements should be developed and diffused.
  - c. NGO groups should coordinate to prepare guidelines and training programs for family and community based care.
  - d. NGOs should train facility managers and community leaders.
  
2. *National plans and evaluations*
  - a. Government policies on the availability of care should be clarified.
  - b. NGO strategy development should be fostered and a national meeting presenting data and studies should be convened.
  - c. USAID evaluation of food security programs should include the coordinated participation of NGO groups.
  - d. An array of large scale, long term strategies with NGOs, facilities, and government needs to be developed.



## APPENDIX: ESSENTIAL DOCUMENTS, HAITI ORPHAN SUPPORT PROGRAMS

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