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YouthNet

Adolescents: Orphaned and Vulnerable in the Time of HIV/AIDS

by Claudia Daileader Ruland, William Finger, Nancy Williamson, Sharifah Tahir, Stephanie Savariaud, Ana-Maria Schweitzer, and Kathleen Henry Shears

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Family Health International, YouthNet Program

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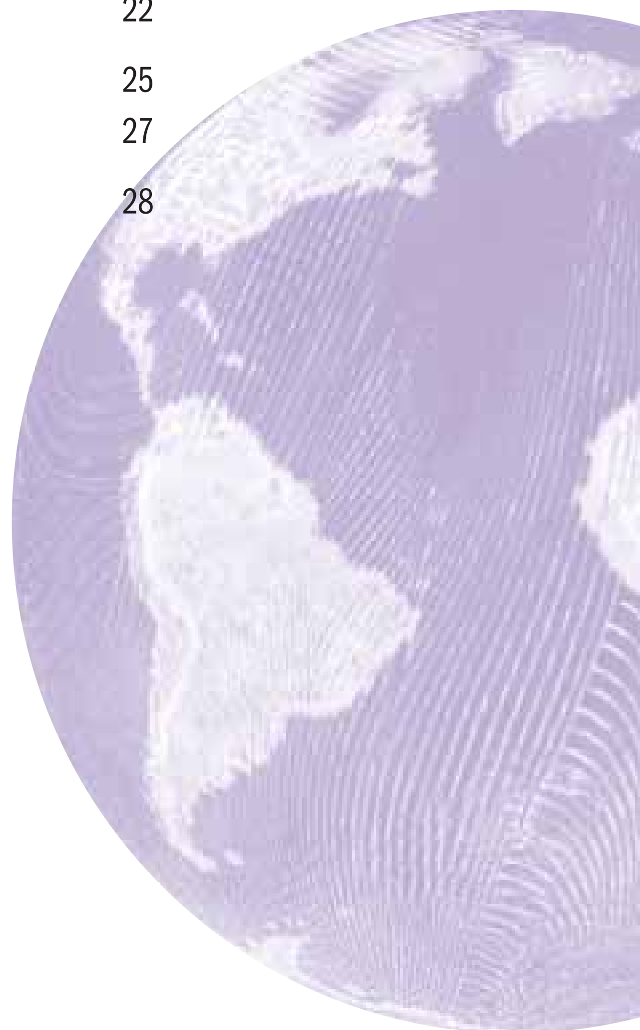


Introduction

Young people who have lost one or both parents have multifaceted needs, particularly in the era of AIDS. Adolescent orphans require different kinds of assistance than children; in some ways their needs are more complex than the needs of younger orphans because of physical and psychological development during puberty and the steps needed to move toward independence and adulthood.

Worldwide, the number of orphans would be decreasing except for AIDS. About eight of every 10 of those orphaned due to AIDS live in Africa. Perhaps the most important statistic for this paper is the fact that an estimated 55 percent of all orphans under age 18 are adolescents.

Despite the demographics, most programs working with orphans do not focus on the particular needs of adolescents: secondary education or livelihood training, sexual and reproductive health education and services, psychosocial and social support for the difficult transition to adulthood, and adult mentors as role models.

This paper first introduces the key issues regarding orphaned and vulnerable adolescents in the time of HIV/AIDS, including the developmental needs specific to adolescents. The second chapter summarizes the limited studies and programs working primarily with adolescents orphaned due to AIDS. Following are four case studies that demonstrate different strategies for working with adolescent orphans and other youth vulnerable to HIV/AIDS, reflecting different cultural and programmatic approaches relevant to Africa, Asia, and Eastern Europe. The last chapter presents conclusions and recommendations based on key themes that emerged in this analysis and identifies priority areas for further research.

This paper calls for greater attention to orphaned and vulnerable adolescents by agencies working in this field. We hope it can stimulate dialogue on some difficult qustions, for example: How can the United Nations framework for addressing those orphaned and vulnerable in the time of HIV/AIDS be utilized better for adolescents? Are there particular program strategies that work best for meeting adolescent needs?

We hope that this paper will assist those who work with adolescents orphaned and vulnerable due to HIV/AIDS throughout the world to better address the unique needs of this growing population of youth.

— Dr. Tonya Nyagiro, YouthNet Program Director

Chapter 1. Living in the Time of HIV/AIDS

In a commercial farm community in Zimbabwe, far away from mainstream society and with no extended family nearby, 10-year-old Honest and his six-year-old sister, Jane, began living alone when their mother died. For more than four years, they have barely managed to stay together, remain in school, and find enough to eat with the help of teachers, farm supervisors, local welfare officials, and the Farm Orphan Support Trust of Zimbabwe, one of hundreds of small nongovernmental organizations (NGOs) and faith-based groups working with communities and families to support orphaned children.

Now, Honest and Jane, like hundreds of thousands of other vulnerable children affected by AIDS, are moving into their adolescence. Many others are already in their teen years when they begin caring for a dying parent or are left with no parents in the home. In this stage of life, moving from childhood to adulthood, Honest and Jane face the same problems of survival as before but now have to cope with still more risks and issues related to adolescent development.

This paper addresses orphaned and vulnerable adolescents in the time of HIV/AIDS. It is designed to stimulate greater discussion of, and advocate for more attention to, the importance of adolescent-specific issues among orphans affected by AIDS, including program approaches for working with adolescents and affected communities. This paper seeks to move the international effort forward more rigorously to identify, describe, evaluate, and expand successful strategies for working with adolescents orphaned and made vulnerable by HIV/AIDS.

There is a danger in focusing on orphans because this approach could exclude larger groups of vulnerable youth. Identifying orphans separately can also contribute to

Adolescent boys play a game outside a youth camp for orphans in Rwanda.

stigma for the youth and family, create ethical dilemmas in qualifying for services, and artificially separate groups of youth who face similar challenges. This paper recognizes and shares these ethical and practical concerns. However, addressing the needs of the many different groups of vulnerable young people presents challenges that are beyond the scope of this paper.

Terms Used in This Paper

The paper avoids using the term "AIDS orphan" because it can contribute to "inappropriate categorization and stigmatization of children," say proposed guidelines from UNAIDS, UNICEF, and USAID.*

The term "adolescence" describes the transition from childhood to adulthood that is marked by distinct biological, cognitive, and sociocultural changes. The World Health Organization identifies adolescence as ages 10 to 19. Some societies and cultures mark the transition to adulthood not solely by physical changes or by the attainment of a certain age but by specific rituals through which young people must pass in order to be considered an adult by the standards of the community. The United Nations Convention on the Rights of the Child defines childhood as up to age 18. This paper uses the terms "adolescents," "teenagers," "youth," and "young people" interchangeably to refer to youth ages 10 to 19, unless otherwise noted.

* Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations Children's Fund (UNICEF), U.S. Agency for International Development (USAID). *Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework for Action.* New York: UNICEF, 2004.

Thus, this paper does not address issues specific to groups of vulnerable youth that might be considered the most marginalized and require particular program emphases — such as street children, child sex workers and victims of sex trafficking, child labor, child soldiers, and HIV-infected youth. For more discussion on how to target services to such marginalized groups of youth, see *Reaching Out of School Youth with Reproductive Health and HIV/AIDS Information and Services. Youth Issues Paper 4*.[1] Recent research and program efforts also provide some guidance on addressing the needs of HIV-infected youth.[2]

This paper does address some vulnerable youth affected by HIV/AIDS in addition to orphans, such as those who have HIV-infected parents, come from poor households that have taken in orphans, are discriminated against because of the HIV status of family members, or live in areas with high HIV infection rates. A recent study showed that adolescents were in some ways more vulnerable before a parent died than they were the year after the death. They had significantly more emotional distress, negative life events, and contact with the criminal justice system than other youths, but these behaviors did not remain significantly higher one year after the parent died.[3]

Needs of Orphaned Adolescents

All adolescents face key developmental tasks, which may be particularly challenging for orphans. The services needed for adolescents who are orphaned go beyond housing, food, social supports, and education — needs that adolescents share with younger orphans. This paper focuses on the ways that programs can address the needs of orphaned adolescents in the context of these developmental issues. While programs serving orphans may include adolescents, they rarely focus on needs particular to ages 10 to 19.

A key developmental adjustment is physical and sexual maturity. With this maturation comes the need to understand relationships, including intimacy and peer pressure. Moving toward adulthood also involves challenging rules, testing cultural norms, finding a means of economic support, and navigating risky behaviors.

Connectedness to parents, including parental expectations regarding school completion, is one of the key protective factors associated with positive outcomes for young people. One positive outcome is avoidance of risky sexual behaviors.[4] Sexual activity, as well as substance abuse and other risky behaviors, often begin during adolescence. Psychosocial and economic distress, which are common pressures for orphans, can heighten these risky behaviors.

Moreover, adolescents in general often lack the information, skills, and access to youth-friendly services needed for positive behaviors regarding their sexuality. Without the protective factor of having parents, adolescent orphans are more vulnerable to HIV infection themselves, as well as to other sexually transmitted infections and unintended pregnancy.

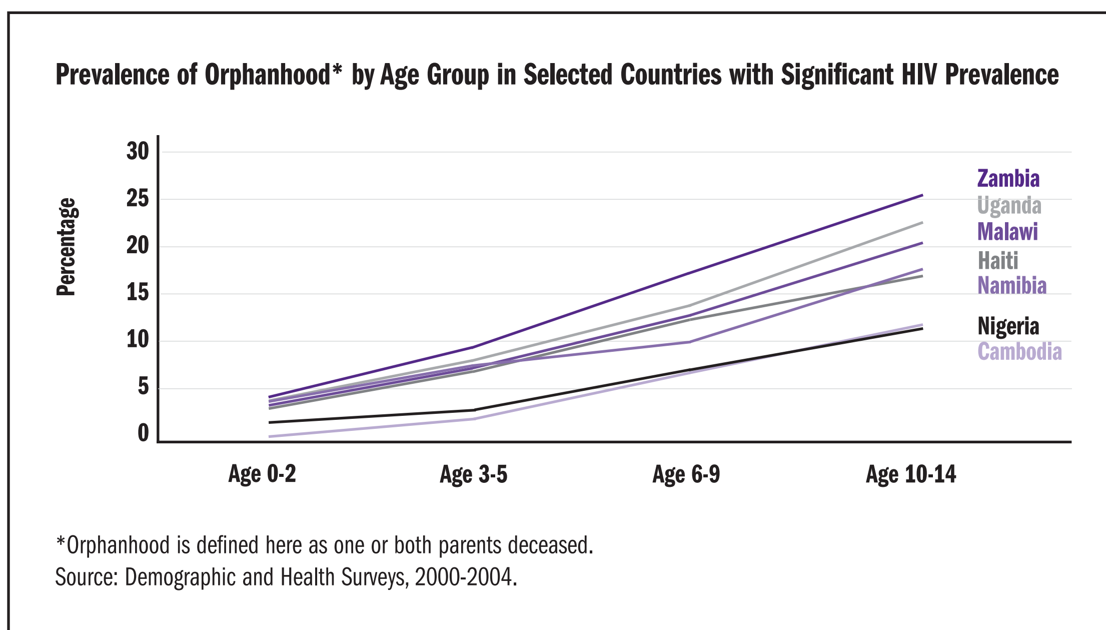
Adolescence involves moving toward social and economic independence, including exploring livelihood options and secondary education. Staying in school past the primary years involves more challenges for adolescents who must pay fees themselves (or with community support) or help support a family. Orphaned adolescents often have more demands placed on them to become household caretakers or income earners. High unemployment rates and lack of secondary or vocational schooling opportunities exacerbate the problem.

"The economic impacts of HIV/AIDS on households jeopardize many adolescents' chances of staying in school, especially if they have to assume new responsibilities for supporting the family," reports *Children on the Brink 2004*, a publication of the Joint United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Children's Fund (UNICEF), and the U.S. Agency for International Development (USAID). "Some become the head of the household if the alternative is for siblings to be separated or if siblings risk losing their inheritance after the death of their parents." Orphaned adolescents then face the difficult choice of working or attending school. "Economic hardship can also deprive adolescents of much needed recreation and participation in community activities. Depression, hopelessness, and risky behavior can be common reactions to these circumstances that need special attention and strong protective measures."[5]

Adolescents often experience emotions of anger, resentment, hopelessness, and depression. Losing a parent or close family member heightens these feelings. "They may seem to be coping, but at the same time they can experience depression, hopelessness, and increased vulnerability," reports *Children on the Brink 2004*. "This can lead to a sense of alienation, desperation, risk-taking behavior, and withdrawal." These behaviors can in turn further increase vulnerability to HIV.

The Majority of Orphans Are Adolescents

About 55 percent of all orphans are ages 12 to 17, according to recent estimates reported in *Children on the Brink 2004*.[6] Data suggest that adolescents make up the majority of orphans in all countries. Data are not available on the exact percentage of adolescents among those orphaned due to AIDS. AIDS often kills parents years after the infection, thus increasing the chance that a child will become an adolescent before becoming an orphan, explains one study.[7] Also, many orphaned as children grow into adolescence, as Honest and Jane have done in Zimbabwe.



Orphaned due to AIDS, these children in Cambodia live with their grandfather, who is working with a CARE/Cambodia official to get assistance with food, clothing, and psychosocial support.

There are a total of 15 million orphans due to AIDS, with some eight to 10 million more expected by 2010, based on estimates in *Children on the Brink 2004*, which expanded its analysis, going from age 15 up to age 17.*

Data from household surveys conducted by the Demographic and Health Surveys show that the prevalence of orphanhood gradually increases as youth age increases (see figure, page 5). While data are only available through age 14, the pattern is obvious — the prevalence of orphans increases with age. This trend underscores the critical importance of programs recognizing and addressing the particular needs of adolescents.[8]

Program Approaches

This paper summarizes research findings from scientific literature and programmatic examples that address adolescence and orphans in the context of AIDS.

In addition, the paper presents four original case studies highlighting different strategies for working with adolescents orphaned by AIDS. The projects represent four types of programmatic approaches. They also represent different regions of the world, because cultural traditions influence programmatic responses, as does the severity of the problem of orphans due to AIDS.

The case studies are based on site visits made in 2003-2004, when the respective writer (identified in this paper's acknowledgments section) interviewed various stakeholders and youth involved in each project. The writers reviewed documents relevant to the country and the program strategy used, including broader international documents. The four strategies are:

- **Community-Based Integrated Services.** Adolescents are part of a larger program that reaches children and youth of all ages with social welfare, education, psychosocial support, and community empowerment activities, illustrated by the Children in Distress project in Cambodia.
- **Youth Involvement and Service.** Through providing care and support services for adults who are dying, youth meet the needs of both adolescents in the homes and the volunteers who are orphans themselves. The anti-AIDS clubs in Zambia are an example of this strategy.
- **Camp Activities and Psychosocial Support.** Outdoor activities in a camp setting, using principles from the Outward Bound program, focus on psychosocial support, as shown through the Masiye Camp in Zimbabwe.
- **Group Homes.** In certain circumstances, group homes can effectively support adolescent orphans with special needs, as shown through a project in Romania.

* The number of orphans due to AIDS projected for sub-Saharan Africa is 18.4 million, but insufficient data exist to project numbers for Asia or Latin America/Caribbean (LAC) regions. Assuming a conservative 5 percent increase of new orphans in LAC and Asia due to AIDS, the worldwide projection for 2010 would be 23 million.

Chapter 2. Caring for Orphans: Research and Programs

The United Nations (UN) has identified a basic framework of action for working with orphans and vulnerable children affected by HIV/AIDS.[9] It adopted the framework through a collaborative process with donors, UN agencies, foundations, NGOs, faith-based organizations, academic and research institutions, and other civil society organizations. The framework was endorsed in 2004 by the UNAIDS Committee of Cosponsoring Organizations and includes five key strategies:

1. Strengthen the capacity of families by prolonging the lives of parents and providing economic, psychosocial, and other support.
2. Mobilize and strengthen community-based responses to provide support to vulnerable households.
3. Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration, and others.
4. Ensure that governments protect the most vulnerable children through improved policy and legislation and by channeling resources to communities.
5. Raise awareness through advocacy and social mobilization to create a supportive environment.

Community-based care is the dominant model of care promoted by experts in the field, rather than long-term institutionalization of children in orphanages and other facilities. The community is best able to identify the young people most at need for interventions, although governments may select target regions or communities for program implementation. While orphanages may be a short-term solution of last resort for some adolescents, institutions separate them from families and communities and are far more costly per child than family- and community-based care.

Since the problems experienced by orphans and other vulnerable youth begin well before the death of a parent, identifying and caring for youth affected by HIV/AIDS needs to start early, including when sick parents are receiving care and treatment. Services for orphans and other vulnerable youth should be integrated with the elements of comprehensive care such as prevention, counseling and testing for HIV, prevention of mother-to-child-transmission of HIV, and others. Since AIDS can affect entire families, a family-centered approach is generally the most appropriate. With family-centered care, HIV-infected individuals are encouraged to bring spouses, children, and other family members to a center for screening, care, treatment, and support.[10]

"Since father died, I have had no clothing and food. Neighbors mistreat me. They chase me away at meal times. I go back home telling my mother that they have sent me away so I can't eat."

– Nelison, Tanzania

The following discussion is organized by the five UN program strategies, including both research findings from scientific journals and programmatic examples.

1. Strengthen Capacity of Families

While advocates emphasize the need for extended families to support orphans, research suggests that many families lack the capacity for this task. Moreover, relying on overstretched or distant family members for assistance can lead to traumatic situations that can marginalize some adolescent orphans.

In Lesotho and Malawi, a study found that orphaned youth were generally considered the responsibility of their kin, not the community, and many migrated away. While some who migrated settled into a new community successfully, usually with extended family, others went into unhealthy family situations. "It was hard to stay with my uncle as he was just a cruel man," said one. "The other children didn't do any work, just me." The study identified 65 youth who had migrated as a result of a parent's illness or death, with one-third of them migrating more than once, some as many as five times. Researchers identified the study group through a survey of more than 800 youth in schools and focus groups involving more than 200 youth, including some living on the street and in institutions.[11]

Strengthening the capacity of families is one way to address difficult psychosocial issues of adolescents. A study of psychological issues among 193 orphans in the Rakai district of Uganda looked at the locus of control for orphaned children (ages six to 20), specifically between their external environment and their ability to adjust their behavior to it. Using in-depth interviews, including a 25-question depression index, the study found that about half of the orphans fell in the depressed range. In reaction to their parents' deaths, 50 percent felt "very sad and helpless," while another 22 percent were too young to express themselves. The study reported that adolescents losing a parent are more likely to "experience a special case of identity loss." The highest depression scores were among those living in child-headed households, emphasizing the need for a family connection.[12]

A study in Uganda looked at 123 children ages 11 to 15 years whose parents (one or both) were reported to have died from AIDS, compared to 110 children of similar age and sex living in intact households in the same neighborhood. Symptoms of psychological distress were assessed using the Beck Youth Inventories of Emotional and Social Impairment. A multivariate analysis of factors with possible relevance for outcomes on these inventories showed that orphan status was the only significant outcome predictor. Orphans had greater risk for higher levels of anxiety, depression, and anger. The study concluded that high levels of psychological distress among youth orphaned due to AIDS indicate that material support alone is not sufficient for these children.[13]

More work needs to be done to find ways to help families address these challenging issues related to child-headed households, migration to extremely vulnerable situations, and depression and other psychosocial issues.

2. Mobilize, Strengthen Community Responses

Like families, many communities are overwhelmed by the growing number of orphans, particularly in Africa. A study in western Kenya, for example, found that one of three children below age 18 had lost at least one biological parent, and one in nine had lost both parents (double orphan). The high numbers of orphans have overwhelmed the capacity of the community and traditional kinship patterns to care for the children, leaving nearly one of every five double orphans in a household headed by a sibling under age 18. "Though community-based interventions are urgently needed as the most appropriate way to address the issue, the complex, local reality in which cultural factors, kinship ties, and poverty are interwoven needs to be taken into consideration if sustainable solutions are to be found," concluded the study.[14]

Some adolescents are living in child-headed households, although this is not a typical long-term living arrangement. A study in Zimbabwe of 43 child- and adolescent-headed households concluded that community groups can help cope with this phenomenon by encouraging the establishment of volunteer-based visiting programs to at-risk households, as well as helping to provide such households with basic material support. Ill or disabled adults lived in 13 of the 43 households; another 13 reported they did not know any living adult relative. In some, relatives were unwilling or unable to take them. Local churches administer an existing support program called Families, Orphans and Children Under Stress (FOCUS), which identified the households in the study.[15]

In a study of 17 child-headed households in a commercial farm community in rural Zimbabwe (a total of 46 children), researchers had a half-day informal visit in each household, where the

children expressed both fears and hopes about the future. "They [local farmers] say we must go, but where to go? If my parents were alive they would have arranged something," said Shereni, age 15. The strongest hope for one-fifth of the children was a good job; others hoped they could complete their education or attend vocational education. Most felt pessimistic about the future. "Our life will be hell soon," said Eriah, age 17. Among the interventions recommended in the study are providing training in psychosocial support to the community leaders, enabling the orphaned children to talk about their experiences, and developing peer support networks with other youth in the community.[16]

One key aspect of community mobilization is to work with vulnerable youth and their families to build livelihood skills and income-generating activities. Existing institutions can help strengthen the community's response. For example, monks of the Kien Kes Temple in Cambodia provide vocational training and small income-generation funds to people living with HIV/AIDS, orphans, and vulnerable children to improve their standard of living. The temple receives technical support from FHI to strengthen program management and community mobilization, reduce discrimination, and increase compassion. This project helps youth such as 13-year-old Keng Lina, who has managed to stay in school and live with her family in a house where the rent is linked to selling the vegetables they grow. Keng Lina's older sister had left school to care for their father, who was dying from AIDS.[17]

An example of private-sector involvement is in Kenya, where Pathfinder International has developed partnerships with Barclays Bank of Kenya and Citigroup through the Global Business Coalition for HIV/AIDS. The partnership supports a livelihood training project involving orphaned youth ages 15 to 21, who learn carpentry, tailoring, and other skills and are guided to jobs and resources such as credit unions.

3. Ensure Access to Education, Health Care, and Other Services

Research has found education to be a key need for orphaned adolescents. A study in Zimbabwe using data from a household survey involving more than 14,000 children younger than age 16 looked at completion rates from primary school in relation to orphans' household circumstances. The study found that the "greater the number of years it is since the mother died, the smaller is the chance that a young man or woman will have completed school."[18]

Double orphans have the greatest risk of dropping out of school. In Tanzania, the school attendance rate for non-orphans who live with at least one parent is 71 percent compared to 52 percent for double orphans. The study was based on household surveys and did not include those living on the street or in institutions; hence, it probably underestimates the impact of orphanhood on child well-being.[19] Children living in households headed by relatives fare worse than those living with parental heads, and those living in households headed by non-relatives fare worse still.[20] In the study of 17 child-headed households mentioned earlier, one-third of the school-aged children had dropped out of school, especially those in secondary school. "If my mother was alive, maybe I would have finished my schooling," said Timothy, age 20.[21]

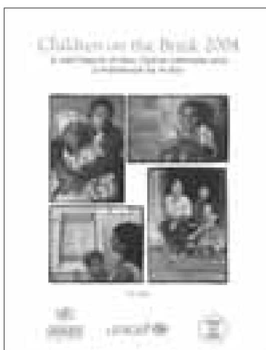
These orphans are living with their grandmother in Zimbabwe.

Innovative programs have begun to address the educational needs of adolescent orphans. An instructional storybook called *Kauna's Birthday Wish* is used in outreach projects in Namibia and is supported by FHI and Catholic AIDS Action.

In the booklet, Kauna lives with her grandmother because her parents have died. Her grandmother does not have the money to send her to school any longer. Depressed, Kauna and her grandmother visit the local pastor, who tells them that every child in Namibia is guaranteed a primary education and explains how they can arrange for this free education.

In another Namibia project called "Schooled for Success," Catholic AIDS Action paid hostel fees and related expenses for 170 needy secondary school students, using a voucher system and home-based care programs. The project uses volunteers to identify and register orphans and vulnerable children, assess their educational needs, advocate for acceptance in selected schools, provide means to continue school attendance, and develop a system of periodic supervision for successful school attendance. The project also emphasized increasing educational opportunities for girls and addressed related issues such as psychosocial needs.

A key need for adolescent orphans is education on reproductive health and HIV prevention, as well as services for pregnancy and sexually transmitted infections (STIs), including HIV. In Rwanda and Zambia, a study among adolescents ages 10 to 19 found that those orphaned experience earlier sexual initiation than non-orphans. In addition, orphanhood occurring closer to adolescent years is more likely to result in early sexual debut than orphanhood occurring in childhood.[22]



Projects have begun to address reproductive health and HIV directly, but more emphasis is needed. In Zambia, the Tizenge Youth Orphans project educates orphans and vulnerable children while also raising awareness about HIV/AIDS and other STIs, along with information on care and support for those who are affected by these diseases. Operated by youth in Eastern Zambia, the community-based initiative works with children ages five to 24 and the communities where they live. Thus far, 13 villages have come together to build three schools, while nine teachers and 30 caregivers have been trained to teach literacy classes, reaching more than 100 students. Other educational activities such as dramas and dances on the topics of HIV/AIDS and STIs have reached more than 3,000 people.[23]

A few projects have integrated reproductive health issues into education programs. A project in four African countries supports Junior Farmer Field and Life Schools, which teach agricultural knowledge, business skills, and life skills to orphans and vulnerable children ages 12 to 18. The schools also address HIV/AIDS awareness and prevention, gender sensitivity, child protection, and sexual health, while providing a safe social space for students to develop self-esteem and confidence. The schools cover traditional and modern agriculture, including field preparation, sowing and transplanting, irrigation, pest control, conservation, harvesting, and marketing skills — knowledge that is commonly handed down within families through the generations. The United Nations Food and Agriculture Organization sponsors the project with the World Food Programme and other UN agencies, NGOs, and local institutions.[24]

4. Ensure Government Protection

Better laws, policies, and support for communities can assist adolescents who are orphans. In the short term, governments can help provide protection and placement for children who do not have adequate family care. A sound and vigorous legal and policy response is necessary to mobilize political and financial resources to safeguard orphaned adolescents' access to education, health care, and other social services, and to protect them from all forms of discrimination, neglect, abuse, exploitation, and loss of inheritance.

Botswana, Malawi, Namibia, Rwanda, and Zimbabwe have specific national orphan policies that include a comprehensive response to orphans and vulnerable children up to 18 years old, outline models of care and support, and identify the roles and responsibilities of various

stakeholders. One of the objectives in Rwanda's National Policy for Orphans and Vulnerable Children is "to provide sexual and life-skills education to girls enabling them to make their own decision and to care for themselves." Other countries like Cambodia, Haiti, and Kenya address orphans and vulnerable children within their national HIV/AIDS strategies.[25] For example, the Cambodia HIV/AIDS strategy promotes "community support for children and adolescents affected by HIV/AIDS."

Uganda has a Children Statute that provides a legal instrument to protect the rights of children, including orphans. The government has created various mechanisms at the national, district, and community levels to facilitate the implementation of the Children Statute and related laws and policies. The Ministry of Justice and Constitution applies flexibility for widows and children to help them defend their inheritance and property rights. Public welfare assistants and Family Protection Units were established at district and community levels. The Association of Uganda Women Lawyers was created to help women and children, particularly widows and orphans, get legal protection.

In Zimbabwe, the Victim Friendly Courts respond to the needs of vulnerable witnesses, including all children who were victims of sexual offenses. These courts offer a child-friendly environment by taking into account children's different cognitive and development stages. In addition, the courts are linked to a multisectoral team that provides counseling, community outreach, and medical treatment (e.g., provision of antiretrovirals or emergency contraception), as well as STI and HIV testing, support, and treatment.

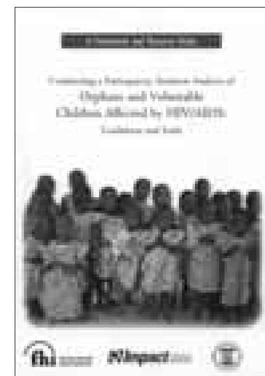
In Jamaica, AIDS is the leading cause of death for people ages 15 to 49, resulting in many orphans. The Adoption Act and Guardianship Act provide a framework for the courts to make decisions in the best interests of the child. Caregivers of orphans under the age of 18 years are entitled to receive an Orphans' Pension subject to certain criteria: the mother must be dead, the father must be dead or unknown, and the child must have permanently resided with the mother before her death.[26]

Benin, Botswana, Kenya, Namibia, South Africa, Tanzania, Zambia, and other countries provide state support to orphans and vulnerable children in the form of exemption from school fees, school feeding plans, grants, or free health care. An example is Tanzania's National Education Fund which pays for the education of disadvantaged children, including orphans and vulnerable children, and has shown a strong increase in school enrollment.[27]

While the growing supportive legal and policy frameworks are encouraging, there are wide gaps in the implementation of laws and policies. Also lacking are data on the extent of implementation, as well as examples of how laws and policies have been used to protect and promote the rights and needs of orphans and vulnerable adolescents. Mechanisms to monitor responses at the policy level, including appropriate indicators, need to be put in place.

5. Use Advocacy and Social Mobilization

The United Nations framework suggests three strategies to raise awareness and create a supportive environment for children, adolescents, and families affected by HIV/AIDS: conducting a collaborative situation analysis; mobilizing influential leaders to reduce stigma, silence, and discrimination; and strengthening and supporting social mobilization efforts at the community level.



A participatory situation analysis process that involves various stakeholders, including adolescents, can be particularly useful in understanding the situation of adolescent orphans and the factors that make them vulnerable to stigma and discrimination. Broad participation helps to enhance social mobilization and promote community actions. Two useful tools are *Conducting a Participatory Situation Analysis of Orphans and Vulnerable Children Affected by HIV/AIDS: Guidelines and Tools* (FHI, 2005) and *Conducting a Situation Analysis of Orphans and Vulnerable Children Affected by HIV/AIDS* (USAID/Africa Bureau, 2004).

Findings from a situation analysis can provide information and community support to influ-

This family in Zambia, now headed by a 12-year-old boy, was orphaned due to AIDS.

ence and mobilize leaders and champions to reduce stigma, silence, and discrimination. This can happen at the national level, which occurred, for example, during the 2002 elections in Kenya. Also, the China Youth Concern Committee and UNICEF recently launched a public awareness campaign that seeks to end discrimination against children who are orphaned due to HIV/AIDS. The first of its kind in China, this campaign includes a song by a celebrity singer and a short cartoon about a lonely child whose life is changed by making new friends.

"To those who have parents who are infected, I leave you with this special message: never give up on life, pray for those who are infected and affected, but don't forget to pray for yourselves. As my mother says, "HIV for me means, 'Hope Is Vital.'"

— Eugenia Imagine Ndlovu, Zimbabwe

Faith-based and other civil society organizations have an important role in strengthening and supporting social mobilization for adolescents by providing information and education on HIV/AIDS, campaigning to reduce stigma and discrimination, and strengthening the capacity of the community to respond to the needs of adolescent orphans.

For example, a large-scale community mobilization project in Zambia called Strengthening Community Partnerships for the Empowerment of Orphans and Vulnerable Children (SCOPE-OVC), implemented by CARE/Zambia and FHI, has reached more than 200,000 children and youth through local NGOs with life-sustaining care and support services. District committees assessed needs, developed action plans, and mobilized resources to implement the action plans. At a SCOPE-supported camp, for example, adolescents could work through difficult psychological issues. "Before I came to camp, I was moody, short-tempered, unfriendly and had a lot of fears," reports Dongo, a 15-year-old orphan due to AIDS. "After being exposed to activities such as games, singing and dancing, praise and worship, and teachings about love, I became a different person. For me, the camp was good, and I learnt about HIV/AIDS."[28]

A community mobilization effort in Namibia called the Philippi Trust focuses on psychological and social issues. Peer counselors are trained to assist orphaned and vulnerable adolescents to overcome difficulties and fears through experiential learning at youth camps. Group leaders ages 16 to 21 are trained in listening and responding skills, with some going on to further training to help lead a six-day experiential learning youth camp for orphaned and vulnerable youth ages six to 18.[29]

Chapter 3. Community-Based Integrated Services: Cambodia

Koh Kong, Cambodia — A group of youth sit in a large room filling bags with rice. Some are from families where one or more parents have died from AIDS. Others are poor youth from the same nearby villages. They are part of a project called Children in Distress (CID), an integrated, community-based approach that works with children of all ages, whether orphaned or not, through social welfare, educational, psychosocial, and community empowerment activities.

CID is part of a larger project coordinated by CARE/Cambodia that works with prevention and community- and home-based care. In 2000, CARE/Cambodia launched CID, which has expanded with support from FHI/Cambodia and USAID.

Cambodia has a national HIV prevalence rate of 2.6 percent, down from 3.3 percent in 1998, and has been noted as one of the few countries worldwide where rates have declined. However, rates remain much higher in the provinces on the Thailand-Cambodia border where two of the five CID sites are located. In this border area, 54 percent of sex workers and 11 percent of police and military personnel are HIV-positive.

The high HIV rates in border areas resulted from an open trade route with Thailand and an influx of money from logging, casinos, and other trading, which led to brothels that appealed to people from many socioeconomic levels. Sex workers operate in brothels, beer gardens, and Karaoke bars. Many of the children in the CID program live with their mothers, who are chronically ill and talk of their husbands going to Karaoke bars before they got sick and died, presumably due to AIDS.

These adolescent orphans work with younger orphans at a center in Cambodia.

The CID project addresses the holistic needs of the youth, rather than just those related to HIV. It uses youth advocates, who get a small stipend (U.S. $1 per day, three days a week), work in the villages where they live, and identify families with chronically ill parents and children who need help. Sum Sitha, director of the CID team in Koh Kong town on the Thailand border, supervises about 20 youth advocates. An energetic and dedicated advocate, Sitha helps involve young participants and allows them to take responsibility. The youth advocates put together the bags of rice and supplies for home-care teams and lead playgroups for the children in the

villages, among other tasks. Some youth advocates come from families affected by HIV/AIDS. Others do not have a parent infected with HIV but have dropped out of school and face an uncertain future.

The CID project works in two areas of Koh Kong province. Koh Kong town is an eight-hour ride from the bustling capital city of Phnom Penh, including four ferry river crossings and very slow driving over a road with major potholes. The other site is the small town of Sre Ambel, about two hours from Phnom Penh via an excellent paved road.

In the village of Boueng Khun Chang outside of Koh Kong town, one family illustrates the challenges of the CID program. The extended family gathers around the arriving CARE jeep. As the grandfather sits on the small platform that serves as a living room above the muddy yard outside the stilted hut, he takes out his daughter's memory book, where she wrote down her feelings, with the help of Sitha and the youth advocate, before she died. She died two months ago; her husband, who cut wood in the forests, died two years ago. A 13-year-old boy, the oldest of the five orphaned children, sits across from his grandfather, attentive and respectful. His eyes seem sad, but his future seems more hopeful with the words on his t-shirt, produced by CARE: "We are joining together to play in the happy children groups."

The grandfather reads the memory book his daughter left: "I had a husband but he is gone," he reads in Khmer, with Sitha interpreting. "During sick, I have no food, I have no medicine, I have no water. I have only my mother and father. My small children have only my mother and father to take care of them." The grandfather looks up, eyes sparkling with a mixture of sadness and courage. "I always tell my children to respect the youth advocates who tell you how to take care of yourself." The memories of the mother continue with a challenging message for a son, who is beginning adolescence and needs a way to recognize and deal with anger at his father.

Koh Kong Youth Advocate

Pon's father worked for one of the prosperous companies that came to the area during the logging boom in the 1990s, but when he got sick, the family started selling property to pay for trips to hospitals in Cambodia and then Thailand, where testing showed he was HIV-positive. When he died of AIDS, there was no more property or income.

Pon, then 16 and the oldest child, quit school and went to Phnom Penh to earn money for the family. Living with his aunt, he earned U.S. $45 a month in the garment industry but sent only about $20 of it home to his mother. He had enough left to go to the bars, where he began to have sex and smoke yama, a methamphetamine available on the street from the synthetic labs that have sprung up in this metropolitan city.

"My father used to take me to the Karaoke bars in Koh Kong when I was about 14," says Pon (not his real name), now clean from his drug habit and back living with his mother. Pon now understands where his father went during those hours he left him alone in the Karaoke bars. "I regret that my father died when he was young and left young children. I am upset with him. A father should take care of his family." Pon's father also left his wife infected with HIV.

Now a youth advocate in the CID program, Pon says he "likes the playgroups, teaching the children about nutrition, morals, and HIV/AIDS prevention. I am very happy with the other youth advocates and with the children in the villages. I am trying to change my behavior and go a good way in the future. If I have a wife, I will be faithful and not go to the brothel. Now I understand HIV is very dangerous to me and our society."

Findings and Observations

Over the first three years of the project, it reached approximately 5,000 orphans and other vulnerable children, many of whom had lost at least one parent to AIDS. About one-third of them were ages 12 or older. The project hopes to expand beyond direct services toward a community empowerment approach, building more self-reliance, increased self-confidence, and hope through such activities as support groups for people living with AIDS and income-generation activities. The project looks at the underlying causes of problems, not at HIV/AIDS in isolation. It also focuses on using the assets of youth, with the youth advocates thriving in the positive structure of teamwork and concrete contributions to service activities.

On-site visits, a review of documents, and interviews with project staff, youth advocates, villagers, and ministry officials led to these findings:

1. **Succession planning assists many youth with family relocation and housing, and it has the potential to address psychosocial needs.** The project counsels parents who are

terminally ill to find appropriate housing and living situations for their children and to develop memory books to record their feelings before dying. Counseling about housing and family location has often been effective, but using memory books to their full potential has been challenging. CARE staff have observed that the village women write mostly about their immediate feelings or thanks for receiving support and less on reflections that may be helpful to the surviving youth. Even so, it is a record by a parent, where keepsakes for their children are few.

2. **Educational and vocational training needs are challenging.** Many of the village children lack resources to purchase school uniforms and pay fees necessary to stay in school. There are no formal fees required for secondary school but informal fees to teachers serve to supplement their meager salaries. Obtaining vocational training is equally challenging. Currently, the orphanage in the town has a small training center with about eight sewing machines for girls and two barber chairs for boys. Sitha hopes that training can expand to include more practical skills for the local area, such as bicycle repair.

3. **Psychosocial support visits meet immediate needs and provide a more in-depth approach.** The CID staff teams with youth advocates in visiting families to assess and meet their needs. The teams help with school uniforms, hygiene products, rice, and referrals for other services, including to the Department of Social Affairs. The teams provide emotional support as well. More structured mental health services for children and adolescents are not generally available, however. The CID team, as a result of findings from a well-being assessment of adolescents affected by HIV/AIDS, plans to initiate adolescent support groups and individual counseling.

4. **Therapeutic playgroups provide many benefits.** These are designed to integrate orphaned children with other children in an atmosphere that helps reduce stigma, allows the children to have fun, and teaches some basic skills in hygiene and HIV prevention. In the playgroup observed in a village of about 70 shacks outside of Koh Kong, four youth advocates led about 100 children, from preschoolers to young teens, in games and educational activities, covering hygiene and HIV/AIDS prevention information. Children swung hula-hoops, played games, worked puzzles, painted pictures, played hand drums, and got haircuts. The vibrant and positive spirit among the children, the youth advocates, and the village adults who helped clearly provides a therapeutic experience to people struggling with death from AIDS after decades of war. Upon returning to the office, the youth advocates discussed how the group went, learning from each other and from Sitha and staff members.

5. **Expanding the focus on adolescents requires more resources.** The project could do more for adolescents if it had more resources. It is considering such additions as adolescent theater groups, support groups, and individual counseling, led by youth. The project could also consider:

- Expanding the impact of the memory books using a more structured, guided oral history approach, where the youth advocates and adolescent family members would interview terminally ill parents about their lives — where they grew up, how the wars affected them, how they see cultural changes, and their hopes for their children's futures. Inexpensive CD recording devices are available to record the stories for the surviving children. The interview process can be empowering for both parties involved.

- Incorporating services that the youth advocates currently provide into for-credit school courses, adding a formal reflective process to their work. Service-learning programs, where youth write papers and create other projects showing what they have learned from the services they provide, have been shown to have a positive impact on students. Also, curricula for out-of-school youth that have been developed in some countries to help youth pursue higher education might be considered.[30]

Chapter 4. Youth Involvement and Service: Zambia

Mansa, Zambia — In northern Zambia, young people work through anti-AIDS clubs as volunteers helping neighbors who are HIV-positive. They are also able to identify and help youth in the households where parents are infected and dying. The volunteers, many of whom are orphans themselves, benefit from this work in terms of their own sexual attitudes and behaviors and personal growth.

"Orphans are the order of the day here," said one young man at a local anti-AIDS club. "It's hard to take care of yourself and your brothers and sisters, *and* to go to school, but look at me, I am working hard."

Almost one of five Zambians under age 18 is an orphan, and a similar percentage of all Zambians are estimated to be infected with HIV, according to a 2004 summary from UNAIDS. All schools in Zambia are required to form anti-AIDS clubs to give students the opportunity for involvement in HIV prevention and education activities. Some clubs have members who are out-of-school youth.

In March 2000, Horizons/Population Council, in collaboration with CARE International and Family Health Trust, began a quasi-experimental operations research project to see how well-trained youth could provide care to people living with HIV and AIDS and to see how such activities would affect youth's own HIV prevention behavior and stigma reduction. Many of these young people were already helping to care for sick relatives without any training or support. While focusing initially on meeting the needs of clients, the study unexpectedly found that the trained youth caregivers increasingly recognized the needs of orphaned children, including other adolescents.

In a formative research phase, participatory methods with anti-AIDS club members ages 13 to 24 in the Luapula and adjacent Northern provinces revealed wide support for youth involvement in care and support. The study then identified 30 anti-AIDS clubs in Luapula as intervention sites and 30 anti-AIDS clubs in Northern province as comparison sites. Members of all 60 clubs received basic training in club management and HIV prevention, as well as materials for recreational activities. The members of the 30 clubs in Luapula province, including the Mansa area, also received training in care and support, in how to network with existing resources and services (NGOs, clinics, and home-based care teams), and in how to conduct stigma reduction activities. Care and support activities were not actively promoted among the anti-AIDS clubs members in the comparison Northern province.

Local health professionals trained the members of the anti-AIDS clubs to provide care and support to their clients. More than 300 club members underwent training, which included role-plays, presentations, discussions, testimony from people living with HIV/AIDS, and sharing personal experiences in care provision. All of the clubs received materials to assist the caregivers, including basic medical kits; pens and notebooks to document their experiences; and bags, aprons, and badges that would identify the young people as youth caregivers in the community. Each club also received two bicycles to assist caregivers in getting to their clients and to help bring clients to medical clinics when necessary. One essential component of the training was a field

activity enabling club members to gain first-hand knowledge of clinics and voluntary counseling and testing (VCT) centers, so that they would know the health workers and be able to inform clients about available services. Repeat trainings were held and continue still on a yearly basis, with supervisors available for the young people if they have questions in the interim.

"We didn't just learn about physical needs during the training," reported one young man during the site visit. "We also learned about human rights and how to care about others. For example, if we come across an orphan who has been rebuked by his adoptive family, we have skills to teach the family to accept him."

A typical home visit begins when teams of two young people call on a home in their village. "First we spend a few minutes talking with the family there, then a few more minutes in prayer, and then ask how we can help," explained a young woman of 16. The teams usually consist of a young man and woman from the anti-AIDS club, who divide the tasks that need completion. They make one to two visits per week.

The hardest tasks include digging latrines, making bricks, or cutting firewood. The young men typically perform these tasks, while the young women fetch water, cook, and clean. Both team members clean the sores of the sick; the clubs provide them with kits containing soap, band-aids, topical antiseptics, and gloves. While gender distinctions are obvious in the division of labor, the participation of males and females as youth caregivers ensures that any task can be completed. "The [client] doesn't mind if you're a boy or a girl, they are just happy for the help," said one young man. "But there are some jobs that are best done by girls, like bathing another woman." Sometimes young people take the very sick to local clinics for medical care; a lack of reliable transportation and roads filled with potholes make this one of the most difficult jobs.

Based on baseline and post-intervention data, the study found that youth in the intervention site were able to provide help with cleaning, nursing care, counseling, and making clinic referrals, and clients reported satisfaction with those services. However, young people felt poorly prepared to provide material needs such as food, medicine, and transportation. After the intervention, youth reported increases in their comfort level in providing care to clients living with HIV or AIDS (72 percent to 91 percent for females; 81 percent to 90 percent for males). Also, youth in Luapula became significantly more aware that they are potentially at risk of HIV infection. Males who believed they were not at risk of infection dropped from 76 percent to 31 percent, with a drop among females from 89 percent to 41 percent. Smaller declines were visible in the comparison area, where youth received prevention training. The number of sexual partners reported by the youth remained relatively steady during both rounds of interviews. Reported condom use among sexually active youth increased only at the intervention site, although it was already high in both study sites. Abstinence was already high in the intervention site and did not change significantly.[31]

Many children in the homes the youth visited had stopped attending school in order to care for family members and secure income. The youth caregivers involved orphans in recreational activities that reduced their isolation, contacted

These four siblings in Zambia were orphaned due to AIDS.

schools if they were inappropriately absent, and made referrals to NGOs that could further address the needs of orphaned children. "As an orphan, I think I can identify with the others," said one young volunteer. "I know what their needs are." Adolescent orphans have specific needs, such as social concerns, said anti-AIDS club members. "And they usually do not continue school in favor of working."

Findings and Observations

The findings and observations are based on a visit to Mansa after the Horizons study was complete. The site visit included meetings with more than a dozen anti-AIDS clubs and interviews with staff involved in the ongoing project, as well as a review of the existing research.

1. **Involving youth in caring for people living with HIV/AIDS led to the identification of, and assistance to, adolescents who were or would soon be orphaned.** The Horizons project originally sought an innovative way to provide care for those living with HIV/AIDS. What emerged unexpectedly was a valuable lifeline to the orphans in these households. Moreover, because the trained caregivers in this case were youth themselves, the connection with adolescent orphans in the households was stronger, and the motivations were strong on both sides to take productive actions.

2. **In areas with high HIV prevalence rates, youth involvement in HIV projects tends to integrate orphans with other vulnerable youth.** The youth in the anti-AIDS clubs providing care to people living with HIV/AIDS included orphans. This information emerged through the Horizons study and during interviews in the site visit for this case study. Integrating orphans with other vulnerable youth in service projects and other interventions can help orphans remain integrated in the community and benefit from social networks among youth rather than becoming isolated.

3. **Community-based projects involving orphans should explore more formal service-learning approaches.** The involvement of youth in providing services in these Zambian communities has been a valuable learning experience for the youth, including the orphans among the volunteers. Some of these vulnerable youth face difficulties in remaining in school. The service experience through the anti-AIDS clubs offers ongoing learning opportunities. Research projects have documented the impact of such "service-learning" projects, formalized in some schools in the United States and elsewhere, where students reflect on the service-learning process through a structured class assignment (papers, drama, art exhibits, etc.). These Zambian youth could benefit more by articulating the process of their learning and service and by receiving formal school credit for doing so. A serious-faced teenage boy, still wearing the green smock that identified him as a youth caregiver, described what he learned this way: "Only when a cure is found will I quit [caring for others]."

Chapter 5. Camp Activities and Psychosocial Support: Zimbabwe

Masiye, Zimbabwe — In the heart of the Matopos National Park near Bulawayo in Zimbabwe, 60 young people — ages 16 to 19 — climb two mountains, cross a river, and finally get to a cave where the San people, who inhabited the mountains more than 1,000 years ago, drew paintings of the animals they used to hunt. Most of the youth are orphaned by HIV/AIDS, and many head their own households.

"What you did today, it's like the journey of your life. You crossed rivers, climbed mountains, you had times where you wanted to give up, but in the end you got there, happy to see the wonderful legacy of your ancestors," says Ezekiel Mafusire, the director of the 10-day camp, standing in front of the cave after the 30-kilometer walk. Using such outdoor activities, the Masiye Camp in Zimbabwe provides valuable psychosocial support to adolescents orphaned or affected by HIV/AIDS.

In Zimbabwe, more than one million young people under the age of 18 are already orphaned, a number that is projected to rise. Almost one of every five children there has lost one or both parents to HIV/AIDS. Life expectancy in Zimbabwe has dropped to 34 years, compared with 52 years in 1990.[32]

The Zimbabwean branch of the Salvation Army has run the camp since 1998 on what is now a 30-acre site with a dam and more than 30 buildings. It supports eight camps a year for about 800 children ages six to 11, 12 to 15, and 16 to 19. "We realized that there was mainly material support for these children — food, clothes, money for school — but nothing was done to help them psychologically. They were depressed, had a very low self-esteem, and lack of hope for the future, which can, in the long run, affect the whole society," explains Stefan Germann, founder of the Masiye Camp and leader of the Regional Psychological Support Initiative (REPSSI), a technical resource network established in Bulawayo, Zimbabwe, in 2001.

Camp Activities

The idea of the camp is based on principles of Outward Bound, an organization that encourages trust and team building through adventure learning. In Zimbabwe, no tradition of adventure camps exists except for a few wealthy private schools. For many children, the camp is their first opportunity to relax and express themselves to someone who listens.

Camp activities are based on building relationships and trust with camp counselors. They include outdoor activities, games, and the facilitation of grief and bereavement processes. Participants go down a mountain on a zip line, walk on a tight rope, and fall in the arms of others in an activity called "trust fall." These activities challenge the minds and bodies of young people. The fear of falling during one of these exercises parallels the fear and despair that young people with sick parents feel; learning to trust their campmates and counselors teaches them to trust others who can help them with the difficulties caused by losing a parent to AIDS. These young people also learn self-reliance, a quality that they must employ to survive during the illness or death of one or both parents.

Admire, a 17-year-old camper, loves the zip-line activity, "… because it's like traveling in the air with a little helicopter," he says laughing.

One favorite activity is the "wall." With help of others, campers must push a person up the two-meter high wood wall, while other campers on top pull him up. "You have to use your mind to get them up, you also have to trust each other," says Christopher, age 17, who takes care of his five brothers and sisters.

"If you take the activities as a metaphor for life, it makes it easier to understand that life is not fair all the time, and that you have to fight for your own survival," says Silethemba, a 21-year-old camp counselor and former camper.

The activities release tension, and the youth become more confident in sharing their stories with camp leaders. "I felt relieved because I had people to share my problems with and you don't bottle a lot of things," says a camper. "I also got different ideas to solve my problems. It was helpful in such a way that our hearts are now free."

The camp includes "ice breaking" sessions to help youth to open up. On the first day, participants are asked to draw a "tree of life." The roots represent their ancestors, the trunk is themselves, the leaves are people who are important to them, and the falling leaves are things they want to leave behind. At that stage, they start talking about themselves and their loss, and many cry. Camp counselors acknowledge that while nearly everyone opens up, some remain isolated and blocked.

At the Masiye Camp in Zimbabwe, outdoor activities challenge orphans to confront fear and increase self-reliance.

Through tales of camp counselors, often orphans and former campers themselves, the feedback from children is astounding. Tichaona, 27, brings out several letters from his room. "We never thought that we would meet people who cared so much about us," says one camper who wrote to Tichaona weeks after the camp session ended. "It gave me the courage that I can do it in life, if I go through hard times, I still can make it with flying colors," writes another.

Findings and Observations

Masiye Camp has been featured in many case studies, is considered a model for Africa, and has been listed in the UNAIDS best practice case studies.[33] The findings and observations below are based on the site visit and a review of this research.

1. **Camp and outdoor activities can help adolescents deal with grief.** Youth affected by HIV/AIDS lack psychological support, especially in the grieving process. "Children are not given the opportunity to grieve properly," explains Mark Kluckow, a clinical psychologist and a consultant for REPSSI. "Our grieving model is a Western one, and we still have to understand a lot of things about grief in Africa, where talking about death is taboo." The project uses the model developed by Elizabeth Kübler-Ross with five stages of grief resolution that progress through denial, anger, bargaining, depression, and acceptance. Kluckow wonders if they need a new model for Africa.

   The spiritual element of the camp takes into account African culture and helps the grieving process. Masiye is a faith-based organization, and morning and evening prayers play an important part without becoming a tool for proselytism. "These children have been raised in a spiritual environment already, and whatever they take at the camp, they will take it back home, and embrace it into a synergistic form between animism and Christianity," says Kluckow.

2. **More work ought to be done to address psychological issues.** Masiye and REPSSI focus on memories during the grief and

bereavement sessions. The leaders acknowledge that African-based grief models need to be developed to include individual counseling and work with dreams. Germann, the Masiye founder, describes an 11-year-old boy who was very bright at school but had difficulties after his father died. "He did not sleep well. After a visit from a child psychiatrist, the child said that he was dreaming about his dad appearing and taking him to death with him. He used to wake up and cry at the end of it. To help him, the psychiatrist asked him to write his dream down with a happy ending, and the boy could read it to himself before going to bed. After a while, the dream disappeared."

3. **The camp helps youth address stigma.** "At school, people point a finger at you because you don't have a uniform, or if they play a game, they don't invite you to join," describes one camper. To fight stigma, one of the Masiye methods is to mix the children — orphans and others affected by AIDS who may not necessarily be orphaned. Some campers still have their own parents, but their parents are also caring for a number of their cousins, and, consequently, no one is able to attend school. This can create stigma against orphans by family members and others their own age.

   Another kind of stigma is called the "lucky orphan syndrome." This occurs when a local organization provides the best clothes or food to young people who can demonstrate orphanhood, while those with parents still suffer from the material consequences of the disease on their own families and may become jealous. The camp tries to nurture a more holistic approach looking after all the children who need assistance, not just orphans.

4. **Youth involvement is crucial.** Communicating with youth is most effective with their active participation. Programmers need to create leadership opportunities for youth and take into account what they already know. Involving young people can transfer lessons into the wider community.

5. **More follow-up work is needed with the youth after the camps and with community-based efforts.** The overall project includes some community-based activities (not the focus of this case study).[34] Linking the camp activities to ongoing work with youth in community settings remains a challenge.

Legacies of Masiye

"My parents were dead and the people I was staying with were not very supportive. I used to get up at 5 in the morning, light the fire, cook porridge, then walk to school (3 km). At 4:30 p.m., I would be back home, I would fetch firewood and water, and cook the meal for the big family. There were nine persons in total, including three younger brothers and sisters. My grandmother did not understand I needed an education; she also used to tell me that I would never get married, because there was nobody to pay lobola (money or cattle paid by the bride's family to the future husband's family).

The camp helped me to know myself, to fight. I realized I had to accept it as it is and not cry all the time. I focused on one thing at a time. Masiye helped me with my school fees for my A level. Now I want to help my brothers and sisters to do the same."

— Silethemba, 21, who worked for the first time as a camp counselor in 2004

"I heard about Masiye at church. A friend of my mother told me about it. I had lost my father. I am the last born of a family of six children. My brother passed away; he was 20 years old. I think he died from AIDS. I learned a lot at Masiye and had a lot of fun. Climbing down a mountain with a rope, I guess it's the same in life, it's hard. It was scary at first, but after doing it, I realized I made it.

At Masiye, you can ask questions to camp counselors you cannot ask your mother. We had educational talks about sex. I used to think I was the only one who suffered, but going to Masiye, you see other people like you. You feel like you have a family.

Masiye financed my school fees until my A level. It was hard though. It was difficult for us to get food and clothing. My mother is sick on and off, my father's family took everything. After school I used to sell food and vegetables. I decided I wanted to help at my local kid's club, because I knew how other children felt."

— Sharon Mbambo, 20, a Masiye camper in 1999 who works for a local organization called Youth for a Child in Christ (YOCIC)

Chapter 6. Group Homes: Romania

Constanta, Romania — When Mariana was 14 years old, she was hospitalized for two months at the Romanian-American Children's Center (RACC) in Constanta. There, she learned that she was HIV-positive. She responded well to antiretroviral (ARV) treatment and counseling. But after Mariana's HIV diagnosis, the aunt who had served as her foster parent would no longer take care of her.

Abandoned by her family, Mariana became a resident of Flower House, one of a network of group homes that rely on the RACC to help them support orphans with special needs, many of them infected with HIV through infected blood. At first, she felt lonely and out of place. Today, Mariana considers Flower House her home. After missing a year due to illness, she has returned to school.

During the 1990s, some 10,000 Romanian children became infected with HIV, primarily through unsafe medical practices. The Ceausescu government prohibited family planning and sex education, which led to large numbers of unwanted pregnancies and abandoned children. These children were commonly treated for anemia or malnutrition with vitamin injections or blood transfusions, often given with reused disposable needles. These practices, including the use of infected blood, led to the Romanian epidemic among children, with the epicenter in Constanta.

In 2001, Romanian physician Dr. Rodica Matusa and her colleagues from the International Pediatric AIDS Initiative at Baylor College of Medicine in Houston, Texas, and the Romanian Ministry of Health founded RACC. Funding from Abbott Laboratories' Step Forward program and the Houston-based Sisters of Charity of the Incarnate Word helped renovate a dilapidated orphanage into a welcoming, state-of-the art facility. Now a staff of 37 health professionals, including pediatricians, infectious disease specialists, psychologists, and social workers, provide comprehensive care and support to more than 500 HIV-infected children and adolescents. About 115 of those youth live in eight group homes in and around Constanta.

Creating New Families

International child welfare experts advocate adoption or fostering rather than institutionalization for orphans and other vulnerable children. In Romania in 2001, prospective adoptive parents usually sought healthy infants, not adolescents and preteens infected with a deadly virus, and fostering children was a relatively new concept. In the 1990s, when half of the thousands of children identified as being HIV-infected had been orphaned or abandoned, Romanian institutional care settings were more like "warehouses" for unwanted children. Group homes such as Flower House were established as alternatives.

Flower House is home to nine young people ages 14 and older cared for by three "social mothers," or house mothers, who work in shifts. Residents of another group home, Speranta House, live in apartments in "families" of three young people and two house mothers. The mothers assign household chores and involve the youth as much as possible in the daily routine. One of the mothers, Raluca, continued to work while she was pregnant. The children took a great interest in her pregnancy and eventually attended her child's baptism. Another mother, Steluta, started working as

a social mother at the request of her HIV-infected son, Marian. Steluta also adopted an HIV-infected boy because Marian wanted a brother. Her adopted son, Ionut, and her Flower House family comforted Steluta when Marian died. Steluta has stayed, dedicating her work to Marian's memory. The Flower House residents also have a father figure in the house manager, who takes them on picnics and camping trips and recently became godfather to Alina, a 14-year-old resident.

Most of the youth attend local schools. Romanian law prohibits discrimination against people with HIV and requires schools to admit HIV-infected children. But in the early years, many of the children did face discrimination. Dr. Matusa of RACC was instrumental in helping HIV-infected children gain acceptance. She went to schools and educated their teachers about HIV, while the youth continued going to school despite their fear of rejection. When the presence of HIV-infected youth in the schools proved uneventful, their classmates gradually overcame their prejudices.

Treatment Evolves

Because of the unique circumstances that created the Romanian HIV epidemic and the increasing availability of life-prolonging ARV drugs, 98 percent of the 527 patients RACC was caring for in October 2004 were ages 14 to 19. Most of them had acquired HIV infection in the 1990s and had developed symptoms of AIDS by the time they came to RACC. At first, health care providers at RACC could not offer their patients antiretroviral treatment. Then, late in 2001, ARVs became available through drug donations from Abbott Laboratories and Bristol-Myers Squibb, and 200 children began taking the drugs. Their effects seemed miraculous. Children who were near death became well and began to grow and gain weight.

Most patients now return to the center for routine check-ups, medical care, or counseling as outpatients. Dental care is provided through the NGO World Vision. This service is invaluable, because even today some dentists do not want to care for HIV-infected patients. Many patients and caregivers participate in counselor-facilitated support groups that include discussions on disclosure of HIV serostatus, adjustment to diagnosis, identity, relationships, and spiritual issues.

Adherence to care is much higher among the Romanian youth than it is among their U.S. counterparts. Measures to promote adherence include counseling and distribution of medication boxes and an illustrated 20-page booklet on HIV/AIDS and ARV therapy. Each youth and his or her caregiver also receive a one-page reference sheet, tailored to the patient, with an actual-size color photograph of the pills the young person will be taking, dosing instructions, and any other special instructions, such as diet recommendations.

New Challenges

In 2004, more than 450 RACC patients were receiving free ARV treatment. Hospitalization rates among the patients have plummeted, and the annual mortality rate among RACC patients dropped from 15 percent to less than 3 percent. Most RACC patients are now teenagers, beginning to struggle with the developmental challenges

Children involved in the group home project perform a dance routine at a dedication ceremony.

of adolescence. Their HIV status has implications for all of these challenges, from developing a sense of their own identity to coping with their emerging sexuality.

The adults who work with these young people at RACC and in the group homes have begun to teach the youth skills, such as vocational skills and money management, that they will need to live independently. An experiment at Speranta House enables some of the older residents to try living on their own in familiar surroundings. A group of five adolescents are supervised by a house mother but are generally responsible for running a new home.

As the youth mature, they come to doctor or psychologist appointments by themselves, and some talk to social workers about sex. Some RACC patients produce and distribute a newsletter, and youth have begun speaking at high schools about HIV prevention and their experiences living with HIV.

Findings and Observations

The following observations are based on first-hand experience working with these patients at RACC, and on those of Romanian and U.S. colleagues who have worked at the center.

1. **Emotional health is as important as medication in keeping HIV-infected youth physically healthy.** At RACC, psychosocial support through individual and group counseling, as well as home visits, includes intensive counseling with families and children and practical assistance in legal issues or material support. This support helps patients accept their HIV diagnoses and adhere to complicated drug regimens.

2. **Multiple factors contribute to high adherence rates and the lack of problems with drug resistance.** These factors include a multidisciplinary staff, highly motivated youth and caregivers, careful attention to factors influencing medical adherence, and a commitment to comprehensive HIV/AIDS care and treatment, including home and palliative care, psychosocial support, and community education.

3. **Reproductive health issues and secondary prevention of HIV transmission have become increasingly important issues as the young people move through adolescence.** Some of them have begun dating. Many fear that they will be unable to have normal relationships, marry, and have children. RACC and Baylor staff members are working with the Ministry of Health, USAID, and seven local NGOs to design a program to improve reproductive health and HIV prevention skills among HIV-infected adolescents in Romania.

Chapter 7. Conclusions and Recommendations

As the number of adolescents who are orphaned due to AIDS and are otherwise vulnerable to HIV/AIDS-related issues expands, the international community must continue to focus more attention on the particular needs of adolescents. This is the largest group of orphans, and they have distinct developmental needs. These include secondary education or livelihood training, sexual and reproductive health education and services, psychosocial support, and social support for the difficult transition to adulthood.

The research and programs summarized under the United Nations framework categories (see Chapter 2) and the four case studies provide examples of how organizations are attempting to understand and address the needs of adolescents orphaned and vulnerable due to HIV/AIDS. Yet, the international community is lagging in developing models, strategies, and approaches that can be expanded and adapted in different cultural settings.

The analysis reported in this paper leads to conclusions regarding the needs of orphaned and vulnerable adolescents. Generally, existing programs are not meeting these needs. The analysis also leads to key gaps in information about this population. The following is a summary of conclusions and recommendations that can help international, national, and local agencies and programs move forward with further action.

Conclusions and Recommendations

1. **Projects working with adolescents orphaned and made vulnerable by HIV/AIDS should address the developmental needs of this age group.** Adolescents have particular developmental needs that can be much more challenging without parents. Programs generally are not addressing the psychosocial, educational, sexuality and reproductive health, social support, and livelihood needs of adolescents who are orphans. In addition, programs need to realize that age and sex differences are important. Developmental needs of younger and older adolescents vary. Girls and boys may also have different needs.

2. **Projects need to pay particular attention to providing reproductive health and HIV information and prevention services for adolescents who are orphaned and vulnerable due to HIV/AIDS.** One of the main protective factors associated with early sexual debut, lifetime sexual partners, condom use, and pregnancy is connectedness to parents. Youth face high risks for infection in general due to the lack of information and services for adolescents in many high-prevalence areas. Being orphaned heightens that risk and highlights the need for reproductive health and HIV information and services for these youth. Programs need to recognize adolescent reproductive health needs and offer age-appropriate information or services.

3. **Programs working with adolescents who are orphaned and vulnerable due to HIV/AIDS need to offer more psychosocial services.** In addition to meeting basic needs, programs need to help youth address issues related to grief, anger, rejection, acceptance, and moving forward with hope. Projects in Zimbabwe, Namibia, and other areas are beginning to address in creative ways

Group activities provide a way for youth to share valuable information and obtain support from peers.

the psychosocial needs of youth orphaned by AIDS, but approaches need to continue to evolve and expand.

4. **Projects need to recognize that youth — including those who are orphans or in a vulnerable situation due to HIV/AIDS — can be major allies and assist in concrete ways in providing services.** Research has shown that involving youth in designing and delivering services can serve as a protective factor for these youth. A study in Zambia found that involving youth as caregivers led to more positive behaviors by the caregivers, some of whom were orphans themselves, and helped to identify and relate to adolescents in the homes. Programs observed in Cambodia and Zimbabwe also showed that involving youth benefits both the youth providing assistance and youth in the households being assisted.

5. **More efforts are needed to assist orphaned adolescents to attend secondary school or obtain livelihood training.** Programs that can integrate livelihood skills development with education would benefit these young people. Primary school ends just as young people enter the first years of adolescence; those who do not or cannot continue their education miss the protective factors that school provides at this vulnerable time in their social and physical development. Many orphaned adolescents are unable to attend secondary school because they must work to supplement the lost income of deceased parents. Scholarship programs and other approaches are needed.

6. **Partnerships among organizations related to funding and program strategies are needed to address the scope of the challenges.** Innovative projects are emerging that provide possible models, such as a large-scale, multipartner mobilization project in Zambia and a UN agricultural education project in four African countries. But more attention is needed to mobilize multiple organizations within specific settings for broad-scale program delivery.

7. **Projects need to utilize faith-based organizations to work with adolescents.** Faith groups have worked with many programs for orphans and provide much-needed compassion and services.[35] At the same time, faith-based organizations may need to expand their ability to address the reproductive health needs of youth.

8. **Program tools, technical assistance, human networking systems, and other resources for orphaned and vulnerable children need to focus more on adolescents.** A valuable tool created by the International HIV/AIDS Alliance and FHI provides online materials on program development, health and nutrition, education, psychosocial support, economic strengthening, living environments, and children's rights. Users can download publications, find out about experiences in particular countries, read about terminology, learn about monitoring and evaluation, and contribute and make comments. Go to: *www.ovcsupport.net*. Another key resource is an online discussion forum on Children Affected by AIDS (CABA), which provides a resource for sharing timely information on effective strategies to assist children orphaned or otherwise affected by AIDS. The Synergy Project hosts the forum on behalf of USAID. Go to: *www.synergyaids.com/Caba/cabaindex.asp*.

Key Questions

The gaps in information identified in this report are summarized below as questions under the five strategies in the UN framework.

1. Strengthen capacity of families

- How can other caregivers be supported to offer the protective influence usually provided by parents?
- What kind of support and services can be given to families to reduce the vulnerability of adolescents before they become orphaned?

2. Mobilize and strengthen community responses

- How do various living conditions affect young people made vulnerable by AIDS?
- What interventions can mitigate living situations that are associated with negative impacts on young people?
- What kind of psychosocial interventions can best help those orphaned to make the transition to adulthood?
- How can communities help prevent orphaned adolescents from becoming street children or sex workers?
- How can communities assist orphaned adolescents, particularly girls, in overcoming stigma and other challenges that may affect their getting married?

3. Ensure access to education, health care, and other services

- What are successful strategies and models for integrating adolescent reproductive health and HIV education and services into projects related to orphans?
- How can additional risks for HIV infection among orphans be addressed?
- Are there differences by sex in school drop-out rates due to orphanhood? How can interventions address these issues?
- Are those adolescents who are HIV-infected themselves receiving proper treatment, including antiretroviral drugs?
- How can HIV treatment and programs targeted to orphaned adolescents be integrated?

4. Ensure government protection

- How are existing laws and policies that address issues related to adolescents and orphanhood being implemented successfully?
- How have laws and policies been helpful in protecting orphaned and vulnerable adolescents?
- What types of new laws and policies are needed?
- Are there successful types of laws and policies that should be adapted or proposed across multiple countries?

5. Use advocacy and social mobilization

- What advocacy messages promoting the needs of adolescent orphans are most effective in mobilizing political and community support for these populations?
- How can communities assess the scope of the issue – including the proportion of orphaned children who are adolescents and the severity of the problems these adolescents face?

9. **Programs need to address priorities for adolescents already identified by international experts.** *Children on the Brink 2004* identified a number of program priorities including those addressed in the recommendations above as well as the following: providing opportunities to connect with adults and observe and learn about adult roles, protecting against abusive labor and sexual exploitation, ensuring adequate nutrition, providing opportunities to develop and maintain close peer relationships, and providing adult support in decision-making.

Organizations working in this field need to address these recommendations and related questions (see box, this page) with additional research, program initiatives, and funding. Such efforts can help expand the focus on adolescents and their particular needs. Ultimately, the goal is to reduce the number of future orphans by providing proper reproductive health and HIV prevention information while supporting those who are surviving the AIDS pandemic to become productive members of their communities.

Young people are part of the promise for the future, the hope of a next generation. While some struggle just to get food to survive, others, like Eugenia Ndlovu, 16, in Zimbabwe remembers what her mother said, "HIV for me means, 'Hope Is Vital.'"

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