CHILDREN & THE HIV/AIDS CRISIS

YOUTH WHO ARE INFECTED & AFFECTED

Booklet No. 5 in a Series on International Youth Issues
Youth Advocate Program International
About Youth Advocate Program International

The mission of Youth Advocate Program International is to promote the rights and well-being of youth on a global basis, giving particular attention to the plight of troubled and needy youth and to those victimized by armed conflict and by state and personal violence.

The Youth Advocate Program International was incorporated in 1994 and is an affiliate organization of the National Youth Advocate Program, Inc. (NYAP). NYAP is a private, nonprofit youth advocacy organization that develops and implements community-based services for troubled and needy youth. It is the parent organization of seven state affiliate programs that offer services in their respective states: Ohio, West Virginia, Indiana, South Carolina, Georgia, Illinois and Kansas. Youth Advocate Program International is registered in the United States as a 501(c)(3) organization.

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Photos: Front: Jym Wilson, © 1999, USA TODAY, reprinted with permission. About the photo: Shamin Nakiganda, 1 1/2, waits to be tested for HIV at a clinic in Uganda. Her father died of AIDS. Her mother is HIV-positive. Back: Courtesy of the Hydeia L. Broadbent Foundation; Carol Friedman, photographer. About the photo: Hydeia Broadbent, age 15, contracted HIV at birth and was diagnosed with AIDS at age 5. Through the Hydeia Broadbent Foundation she and others provide HIV/AIDS prevention and health education programs.

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INTRODUCTION

Most of the readers of this booklet can remember when they first heard about Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). We remember when medical experts were still trying to determine how AIDS was transmitted from one person to another. Realizing the deadliness of the disease, near panic emerged in some communities. But the population group that is focused on in this booklet—children under the age of 18—has none of these memories. AIDS is not a “new” disease for today’s youth. They have lived with the reality of HIV/AIDS their entire lives.

The crisis that HIV/AIDS has created in the lives of children and youth around the world compelled Youth Advocate Program International (YAP-I) to produce this booklet, our fifth in the series on international youth issues. It is a tragedy that young people have the highest rate of HIV infection worldwide. And it is equally distressing that millions of children are orphaned or abandoned and, in some cases, have become the heads of their households because their parents have succumbed to AIDS.

YAP-I’s sister agencies in the National Youth Advocate Program (NYAP) have, for over 20 years, provided community-based programs for youth with special needs and for those whose family structure has been damaged or destroyed. Foster parents and staff in NYAP have cared for HIV-infected youth and mourned when some of those children lost their battle with AIDS.

YAP-I dedicates this booklet to those who are caring for infected and affected youth. We call upon governments, organizations, and individuals to come together to confront the health and social welfare crisis that HIV/AIDS continues to inflict on our children.

Nancy Nye
Director
Youth Advocate Program International
OUTLINING THE HIV/AIDS CRISIS

- HIV is transmitted through an exchange of bodily fluids during sexual activity, by exposure to infected blood, by sharing contaminated needles, or from mother to child.

When an infected person's T-cell count drops below a critical level, or when complications develop, the HIV infection is then diagnosed as AIDS.

AIDS is among the top infectious diseases killing children and youth around the world.

Few other diseases have struck as much fear in people as the epidemic caused by Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS). After years of collecting data about the mysterious wasting disease that resulted in the deaths of millions, AIDS was identified by medical professionals in 1981. Later, in 1983, HIV was identified as the retrovirus that causes AIDS. Although there is not unanimous agreement, many HIV/AIDS researchers believe the disease originated in Africa in the 1950s and that sexual intercourse was the primary mode of transmission. Today, what is certain is that children and young adults worldwide comprise the group with the fastest growing rate of new infections. HIV/AIDS currently has no known cure.

HIV is transmitted through an exchange of bodily fluids during sexual activity, by exposure to infected blood, or by sharing contaminated needles. It also can pass from an HIV-infected mother to her unborn fetus or to infants during the birth process. HIV enters specific cells in the immune system known as T-cells. HIV then replicates and binds onto the T-cells, permanently altering the DNA structure of the healthy cell. When an infected T-cell replicates, HIV emerges from the cell as a new virus capable of infecting and destroying the new T-cells. When an infected person's T-cell count
drops below a critical level, or when certain unusual infections or complications develop, the HIV infection is then diagnosed as AIDS.

A second strain of HIV was discovered in 1986. Known as HIV-2, this infection, while sharing many characteristics with the primary retrovirus, destroys the human immune system more slowly. Because HIV-2 infection is rare in children and few HIV-2 infections have been identified outside of West Africa, children who are referred to as HIV-positive throughout this booklet are assumed to be infected with HIV-1.

An older child or young adult who is newly infected with HIV can remain generally well and not show AIDS symptoms for many years. However, HIV is not dormant during that time. It is reproducing and multiplying—attacking the immune system, the brain and other body systems. Those who are HIV-positive show different symptoms and different rates of progression toward AIDS.

A child who contracts the disease in utero (while still in the mother’s uterus) or during delivery and is born HIV-positive is likely to show signs of AIDS within the first years of life if he or she is not treated with antiretroviral therapies. The rapid onset of AIDS is often due to the fact that a child’s immune system is not fully developed until after the first year. As of 1995, in the United States, 70 percent of children born HIV-positive showed symptoms within the first year, and 17 percent died before their first birthday. With the advent of new medical therapies, however, children born HIV-positive are developing AIDS symptoms later and are remaining well longer.

The World Health Organization (WHO) lists AIDS among the top infectious diseases killing children and youth around the world. Because HIV/AIDS destroys the immune system, HIV-positive children become susceptible to many common infections that are life-threatening for them. These infections include various types of pneumonia, bacterial and fungal infections, and chronic hepatitis. Infected children also are vulnerable to a wasting disease where they experience severe weight loss. Tuberculosis is often the first sign of HIV infection in infants. Older children who were born HIV-positive may show neurological symptoms of AIDS—often appearing as a sudden and marked failure in school. Children with aggressive HIV are often of small stature. Another disease associated with AIDS in older children is shingles—a painful disease which results in blisters that follow the pathway of a nerve.

Who is a child?

Defining the term “child” for the purposes of this topic is complex. The Convention on the Rights of the Child (CRC) defines a child as a person under the age of 18 unless national laws recognize the age of majority earlier. Because every country in the world has ratified the CRC except the United States and Somalia, 18 is accepted as the worldwide standard and is used throughout this booklet. However, HIV/AIDS research organizations have used a variety of designations by age and criteria for adulthood—making discussion of the impact on children under age 18 more difficult.

UNAIDS, the United Nations agency created to deal with the global threat of AIDS, uses statistical data about children and AIDS that divides children into two age categories. “Children” are counted as those under age 15 and “young adults” are defined as those between the ages of 15 and 24. Most HIV-positive children below age 15 are categorized as acquiring the disease while in utero or during birth, through breast-feeding, or through blood transfusions. However, there are children in the world under age 15 who have contracted HIV/AIDS through sexual activity and intravenous drug use.

HIV/AIDS threatens children worldwide

HIV/AIDS is not a disease that discriminates. It does not matter if a child is impoverished or the heir to a multimillion dollar trust fund. A child’s place in society will not protect him or her from HIV/AIDS, although there are categories of children who are more vulnerable. According to Save the Children, “The rapid spread of
HIV/AIDS across the globe in the past decades is inextricably linked to the poverty and powerlessness in which the majority of the world's population lives. Because HIV/AIDS ravages the immune system, it has indirectly contributed to a sharp rise in the number of children's deaths from other infectious diseases, once thought to be on the decline.

HIV-positive children die of AIDS-related diseases, and children not infected with HIV suffer when their families are affected. Because of this booklet's exclusive focus on the HIV/AIDS crisis, children who do not have HIV are described as uninfected. However, this does not mean that these children do not suffer from other diseases or the ill effects of poverty.

**HIV/AIDS myths hurt children**

Myths about HIV/AIDS have spread almost as fast as the actual epidemic. Common misconceptions include the belief that HIV/AIDS is spread through casual contact (i.e. shaking hands, hugging, breathing on others) or by touching restroom fixtures or using eating utensils once used by an infected person. In South Africa, some communities believe that AIDS is a direct result of bewitching or that large women do not carry the disease, only thin women.10

Increasingly, children have been put at risk for HIV/AIDS because of myths about the disease. In several parts of the world, children are being targeted by adults for sexual gratification because it has been rumored, erroneously, that children do not carry the disease. Younger and younger children are being abused because some people believe that children are less likely to be sexually active and, therefore, less likely to be infected with the disease—making them "safe" sex partners.

In South Asia the first reported case of AIDS was in 1986. Originally it was believed to be a foreigner's problem. When the disease spread into the general population, South Asian communities were shocked. Because there was little research available, and much of the population is illiterate, myths and taboos spread rapidly. Some of the South Asian myths include, "sexually transmitted diseases are cured by having intercourse with a young girl."11

**HOW MANY CHILDREN ARE INFECTED WITH HIV/AIDS?**

- Every 60 seconds five people around the world between the ages of 10 and 24 are infected with HIV.
- There are 1.2 million children under the age of 15 living with the disease worldwide.

HIV is most often transmitted to young children from their HIV-positive mothers.

HIV infection rates indicate that children and youth are the most vulnerable segments of the world population. Whether they are born with the disease or acquire it in childhood, children and youth up to age 24 have the fastest growing rate of infection. Every 60 seconds five people around the world between the ages of 10 and 24 are infected with HIV.12 One tenth of all new infections worldwide are found in children under the age of 15.13 In 1998 there were over 590,000 new infections for children under 15,14 (most acquired the disease through their mothers) and currently there are 1.2 million children living with the disease around the world.15

There are several reasons for this disturbing trend that are related to behaviors that put people at risk of contracting HIV. Directly or indirectly, children are infected because of the following factors.

**The migratory patterns of HIV/AIDS and male sexuality**

Economic migration has contributed greatly to the spread of HIV infection throughout Africa, Asia and South America.16 In South Africa, for example, many men travel great distances to find work. They leave behind girlfriends or wives whom they see rarely. Many
men away from home visit prostitutes or have multiple sex partners—increasing their risk of becoming infected with HIV. In turn, these men can unknowingly infect their subsequent sex partners.

Economic migratory patterns have contributed to the spread of HIV through two distinct means. First, mobile populations are removed from traditional norms that help to prevent engaging in risky sexual behaviors. Second, the women in sexual relationships with these men often are very poor and lack access to the information and medical care that could help prevent HIV transmission to their children if their partner infects them.

However, even where men are not migrating long distances for work, cultural traditions that permit men to have multiple sexual partners result in the greater risk of HIV infection for women and, in turn, children.

**Children acquiring HIV/AIDS from their mothers**

Worldwide, according to UNAIDS, approximately 1,600 babies born daily are infected with HIV. That accounts for nearly half a million children a year. Most of these children are born in the developing world. For example, in Thailand it is estimated that 15,000 children are delivered yearly to HIV-infected mothers and in South Africa it is believed that one in five pregnant women is HIV-positive. Some of these women's children will develop AIDS; others will not.

The transmission of HIV from a mother to her child can occur in three ways: in utero, during the birthing process or through breastfeeding. Currently, there is considerable debate surrounding the issue of mother-to-child transmission. Recent studies have shown that the drug zidovudine (commonly known as AZT), if given to mothers before a baby is born, can significantly decrease the baby's chances of in utero infection. A study conducted in the United States showed that when AZT was administered to a mother while pregnant, during delivery, and to the newborn, HIV transmission decreased from about a 25 percent infection rate to 8 percent. Also, many doctors believe that a planned delivery by cesarean section greatly reduces infants' chances of infection.
Breastfeeding by HIV-positive mothers increases their infants chances of infection. Some studies suggest that 1 in 7 babies born to HIV-positive mothers will become infected through breastfeeding. Breast milk provides babies with the antibodies and nutrition needed to fend off other infections that can be fatal to newborns. In parts of the world where clean water and formula are often unavailable, HIV-positive women are left with the dilemma of whether or not to breastfeed a child.

Other ways children acquire HIV/AIDS

In addition to transmission from infected mothers, children can acquire HIV through blood transfusions, intravenous drug use and unprotected sex. Although it is more likely that younger children infected with HIV acquired it either through their mothers or through tainted blood transfusions, experts are concerned that an increasing number of young children are acquiring the disease through sexual intercourse. Children who are the victims of commercial sexual exploitation, war and economic and political crises, and children who are imprisoned are vulnerable to the HIV/AIDS crisis.

Infected blood supplies

In parts of Asia and Africa, 30 percent of the women and children infected with HIV acquired it through blood transfusions. WHO estimates that only 50 percent of all blood donations in South Asia are screened for HIV. However, in countries where the International Red Cross operates, incidents of HIV transmission through blood transfusions are much lower. Officials from Nepal claim that, with Red Cross' guidance, almost 100 percent of its blood donations used for surgery are HIV free.

Drug abuse

Drug abuse among children is an issue confounding parents, educators and leaders in many parts of the world. Drug abuse may result from youthful experimentation with risk-taking or as a means of dulling the pain of living in difficult circumstances. Because there is often little education about exposure to contaminated blood, children who use injection drugs are contracting HIV from dirty needles.

In Burma 60 percent of teenage drug users surveyed in 1998 by UNAIDS and WHO tested positive for HIV. In the same year in Belarus (a former Soviet state) 4 out of 5 registered HIV-positive people were teens addicted to drugs.

Sexual activity

Increasingly, HIV is being transmitted to children through sexual intercourse. It is somewhat expected that older teens are curious about sex and sexuality, therefore many countries have established educational campaigns to teach adolescents about the health risks associated with unprotected sex. However, many older teens adopt an attitude of invincibility and believe that "it won't happen to me." The reality is that adolescents are part of the largest population of HIV-infected people because of their sexual activity.

The lining of a young girl's vagina and a young boy's anus is easily torn, increasing the possibility of HIV infection through sexual activity. In some African countries, the HIV infection rate for teenage girls compared to boys is 6 to 1. Because of their physiology, sexually active girls are much more susceptible to HIV infection than sexually active boys.

Cultural practices that put children at risk

Younger children also are becoming sexually active, often through no choice of their own. Fear of HIV/AIDS has created more demand for children in the commercial sex industry. In Nairobi, Kenya, the rates of HIV infection are rising, and, according to Dr. Sobie Mulindi a professor at the University of Nairobi, there has been a rise in sexual abuse of children because of fear of AIDS. The notion that children probably do not have the disease has resulted in some adults using children for sexual gratification. Dr. Mulindi reports that in some areas it is no longer safe for children to be outside without parental supervision.
In villages throughout Africa and in other parts of the world, children are acquiring HIV/AIDS because there has been little education about how the disease spreads and because of fear of, as well as lack of opportunity for, AIDS testing. For example, in Kampala, Uganda, 16-year-old Namuli was chosen to be "heir to her aunt"—meaning that when her aunt died the young girl was to marry her uncle and raise the children. What Namuli did not know was that her aunt's death from AIDS was the result of being infected by her husband. In turn, he infected Namuli who then gave birth to an HIV-positive son before she realized that she had the disease. Her husband died as a result of AIDS, too. Namuli died at age 27 and left behind two orphaned sons in addition to her aunt's children.

Although traditional practices, such as the one described in Namuli's case, are not intended to harm children, some practices require children to participate in behaviors that put them at risk of disease. In many circumstances, prevailing religious and cultural views directly prevent children from getting the information they need to protect themselves from HIV infection.

Children, particularly girls, are vulnerable to HIV infection because of the soldiering practices of some countries. Worldwide, there are approximately 300,000 child soldiers. Girls make up a small percentage of the child soldier population but are frequently used for the sexual gratification of the male soldiers.

Refugee children and street children also are vulnerable to HIV infection. Displaced from their homes, many of these children turn to drugs and prostitution as means of survival. These children are at particularly great risk because of their precarious living situations. When questioned about HIV/AIDS by the International Rescue Committee only 10 percent of adolescent refugees in the Republic of Georgia (a former Soviet state) could name two ways to prevent HIV infection.

Like adult prisoners, children behind bars are subject to violence, abuse and unwanted sexual advances. Incarcerated children have few if any means to protect themselves against HIV infection.

*See YAP-I's booklet, "Children Behind Bars"

HOW ARE CHILDREN IMPACTED BY HIV/AIDS?

By 2010, it is estimated that 42 million children will be orphaned worldwide because of HIV/AIDS.

In many parts of the world, children have been abandoned by their extended family because a parent had AIDS.

- Production of HIV/AIDS drugs for children lags behind production of drugs designed for adults.

Children are affected by HIV/AIDS, not just infected. Both uninfected and infected children can face abandonment, stigmatization and victimization because the disease has attacked them or a close family member. Many of these children are orphans and, at times, the heads of households at a young age.

The effects of HIV/AIDS on uninfected children

Children who do not have HIV/AIDS, but whose parents or other close family members have the disease or have died of it, may be socially stigmatized in a variety of ways.

Orphaned and abandoned

UNICEF estimates that by the year 2010, 42 million children will be orphaned worldwide because of HIV/AIDS. Ninety percent of these orphans will live in sub-Saharan Africa. However, this is not just a problem for Africa. It is estimated that by the year 2000, the United States will have 80,000 orphaned children as a direct result of parental HIV/AIDS infection. Also by the year 2000 in Thailand 100,000 children under the age of 15 will have lost their mothers to AIDS.
In Zambia, the orphan population is on the rise because of AIDS. In 1990 the country had roughly 20,000 AIDS orphans, UNAIDS believes this number will rise to 500,000 by the year 2000. Alarmed at the number of children living on the streets in Lusaka, the capital of Zambia, local non-governmental organizations, such as Fountain of Hope, have started schools for street children in an effort to give them some kind of education and to try to curtail the rising number of HIV infections in children.

Because orphaned children are not afforded the same educational opportunities as other children, they are even more ill-equipped to deal with the realities surrounding HIV/AIDS. These children often go on to become tomorrow’s victims of sexual and other forms of abuse. The few children that are admitted to orphanages and state run agencies often experience the stigmatization associated with having had a parent who died of AIDS. It is more likely that these children will be avoided or abused by others because of their circumstances. For example, babies in India who have lost one or both parents to HIV/AIDS are less likely than other children to be selected for adoption even if they are not infected with the disease.

In many parts of the world, grandparents who had expected to be cared for by their children are finding themselves in the role of parents again because their children have died of HIV/AIDS, and their grandchildren need care. This is becoming problematic because both children and many older people require special attention.

Children also face difficulties while caring for their sick parents or relatives. A 1994 study in Thailand of 116 households affected by HIV/AIDS found that most of the families faced stigmatization because of the disease, and 20 percent of the families had experienced situations where other families would not allow their children to play with the children of HIV-infected parents. However, on a more positive note, a study in Tanzania has shown that families that have experienced an AIDS death were more likely to accept other families AIDS orphans.

Some children have been abandoned by their extended family because a parent had AIDS. Family members often are afraid to take in these children for fear that they also have the disease. Many extended families simply cannot afford the additional burden of abandoned children or are ill-equipped to raise them. One study conducted in Zimbabwe showed that 88 percent of the families interviewed did not want the orphaned children but felt a duty to care for them. That is why most of the 600,000 children orphaned because of AIDS in Zimbabwe have been taken into their extended families, except when cultural traditions become a barrier to this—as is illustrated in the following example.

In Mutare, Zimbabwe, 15 year-old Willard Tinet, began caring for his two younger brothers after his mother died because, according to custom, his mother’s relatives must come and take her things before the boys can go live with their father’s relatives. Tradition dictates that the father’s family must care for the children if the parents are no longer living. The boy’s extended family from their father’s side must shun them until this happens. Because the mother’s family has been fearful of coming to the home and re-
claiming her possessions, the children have been left to fend for themselves.

**Caregivers**

Children whose parents have become sick as a result of AIDS often find themselves in the role of caregiver and provider for their family. Typically this is an older sibling who sacrifices education and childhood to move into the role of parent. He or she makes the decisions for the family and tries to meet everyone's needs.

In Uganda, where approximately 1.3 million children have been orphaned because of AIDS, children find themselves as the primary caregivers to several younger siblings. Although Uganda is succeeding in decreasing the number of new infections within its borders, it is left with thousands of households headed by a person under age 18.

According to United Nations Development Programme (UNDP) research, “the care that older siblings can provide for younger children is likely to be inadequate because of the increased poverty of the household and the lack of maturity and experience of the caretaker.” Children are subjected to poorer hygiene, developmental delays, school absence, grief, loneliness and feelings of despair as they witness the deterioration of their parents and at times their entire family.

**The impact of HIV/AIDS on uninfected siblings**

There is a hesitancy by caregivers to tell uninfected children of their sibling’s illness because the disease does not show itself rapidly. Siblings may expect that someone with a deadly disease will become debilitated rapidly and die within a short period of time. This is not usually the case with HIV/AIDS. However, as an infected child becomes more ill, the uninfected siblings may experience a great deal of emotional turmoil resulting from anxiety about possibly contracting the disease, social isolation, parental neglect, and the grief of losing a sibling.

**Discrimination**

Many of these children will face discrimination in their attempts to access health care. According to a World AIDS Campaign document, children who are not HIV-positive but have a parent or sibling who is, are at greater risk of dying of preventable diseases because they are discriminated against due to AIDS in the family. In some parts of the world, the health care industry’s perception is that these children are sick therefore they probably have AIDS and investing health care resources is wasteful.

These same children run the risk of being discriminated against in property and inheritance rights if they are the child of an AIDS afflicted parent. Also, many AIDS orphans face educational discrimination. Often these are the children that have been taken in by the extended family and there is not enough money to send them to school. More often than not, these children will be required to work for their food and shelter.

**The effects of HIV/AIDS on infected children**

Children who are HIV-positive are affected by the disease from the moment they contract it. Over time, they experience physical degeneration in addition to social stigmatization— even though new treatments are available that can significantly increase their life expectancy and their quality of life.

**Abandonment and discrimination**

Throughout the world there are many cases in which children are discriminated against because they are HIV-positive. In Thailand the number of HIV-positive babies being abandoned at hospitals is on the increase. According to Save the Children—Romania, HIV-positive children are often denied basic health rights such as dental cleanings because dentists fear that they will lose other patients if they clean the teeth of an HIV-infected child. In many of the regions of the world, adolescent girls are afraid to come forward and be tested for HIV because of community taboos about sexual activity and because of a lack of patient-doctor confidentiality.
Medication and medical care

In the United States, medication is the third largest expenditure for children with HIV, after inpatient hospital stays and ambulatory care. The estimated cost of medication is $6,000-$16,000 annually for each HIV patient. In places like the United States and Western Europe the medicines necessary to control HIV/AIDS are available, but much of the rest of the world neither has access to nor can afford these medicines.

There are U.S. government-approved drugs for children with HIV/AIDS, although production of drugs designed for children lags behind production of drugs for adults. Because children make up only a small percentage of HIV-infected people in some countries, such as the United States, they are often overlooked by advocacy groups, the media, and the drug industry. Drugs are often tested on adults, even though it is acknowledged that children have immature immune systems and different needs where the disease is concerned. The U.S. Food and Drug Administration (FDA) now requires drug companies to test promising new HIV/AIDS drugs to determine the possible effects on children as well as adults.

Even when medication is available, children often are afraid to seek the necessary care for a variety of reasons including unfriendly facilities, the costs of treatment and the risk of being treated in a discriminatory manner because of their age. When they receive proper care, children with HIV/AIDS can live longer and healthier lives. In Europe, children born with HIV have an 80 percent survival rate until their third birthday, but in Uganda 66 percent of children born HIV-positive are dead by age three. Nearly half of children born with the disease in Zambia die before their second birthday.

WHERE IS THE CRISIS MOST SEVERE?

The HIV/AIDS crisis has driven down the life expectancy of people in some African countries by as much as ten years.

- Experts predict that there are between 94,000 and 700,000 children infected with HIV in Asia.
- In the Russian Federation, health care professionals estimate that for every HIV-positive person who has been tested, there are six more who have not been tested.

HIV/AIDS has become a global problem affecting all parts of the world. During the 1980s the problem was identified as a health crisis in North America and Western European countries. Initially it was thought to be a disease that most often struck the homosexual male community. However, it became apparent that the disease did not confine itself to certain prescribed communities but infected millions; young, old, wealthy, poor, homosexual, heterosexual, male and female.

Currently, the rate of HIV/AIDS infection is decreasing in certain parts of society in the United States and many European countries. However, there does remain a growing population of young people who are becoming infected with HIV. (Forty-four percent of all new infections in the United States are among young women.) However, despite the fact that the spread of HIV/AIDS seems to be containable, there are global hotspots and new vulnerable communities that are only beginning to understand the consequences the disease is having on their populations, their economies and their social welfare systems.

Global hotspots

The rapid spread of HIV/AIDS presently seems to be greatest in Africa. The sub-Saharan region of Africa is the site of rising infec-
tion rates and the rapid disappearance of people between the ages of 15-45. The HIV/AIDS crisis has driven the life expectancy of some African countries down by as much as ten years. To date children’s deaths from AIDS is 3.2 million worldwide; 3 million of these deaths have occurred in Africa. Ninety-five percent of all HIV/AIDS orphans are in Africa, and children under 15 are becoming the largest population of new infections. Nine out of 10 new infections in the sub-Saharan region of Africa are currently in this age group. According to the United Nations Secretary-General Kofi Annan some African countries must use half of their small health care budgets to take care of those sick with HIV/AIDS.

Africa has become the HIV/AIDS epicenter for many reasons. According to HIV INSITE there are four key reasons for Africa’s growing problem with the infection rates of children. First of all, Africa has more HIV-positive women of childbearing age than any other continent; second, there are more births per woman in Africa than anywhere else, thus increasing the chances of a mother passing the virus to several children. Third, almost all children are breastfed in Africa and that increases the transmission rates through mother’s milk. Finally, the drugs that decrease the risk of an HIV-positive mother passing the virus to her offspring are not readily available in Africa.

Another reason for the unchecked growth of the HIV/AIDS epidemic in Africa has been African leaders’ denial of the problem. Even while hundreds and thousands of citizens were struck down by the epidemic African leaders turned a blind eye. It took the death of a son from AIDS for Kenneth D. Kaunda, former president of Zambia to finally admit that his country had a problem. In 1989 Kaunda became one of the first African leaders to speak out on the HIV/AIDS epidemic, stating that it could become, “a soft nuclear bomb on human life,” if scientists could not find a cure.

Although the crisis has affected Africa in alarming proportions, India is actually the country with the largest number of HIV-infected people, due to its vast population. Although less than one half of one percent of India’s citizens are estimated to be HIV-positive or have AIDS, that accounts for approximately four million people. Other Asian countries also are experiencing a sharp rise in HIV infections. Experts predict that there are between 94,000 and 700,000 children infected with HIV in Asia.

Although HIV/AIDS did not infiltrate Asia as quickly as it did Africa, the increase is cause for alarm because Asia has the unfortunate distinction of being the continent where several countries house flourishing commercial sex businesses. For example, girls who have been trafficked out of Nepal to India to work in the sex industry are returning home HIV-positive in growing numbers. Most of these girls are from rural villages where health care is insufficient and social stigmatization is high.

Cambodia is one of the countries hardest hit by the HIV/AIDS epidemic. It is currently estimated that one in 30 pregnant Cambodian women, one in 16 soldiers and policemen and, almost one in two sex workers are HIV-positive.

A closer look at an HIV/AIDS hotspot—Uganda

Uganda was one of the first African countries to feel the effects of the HIV/AIDS crisis. By the end of 1997 it was estimated that 1.8
million people had died of AIDS in Uganda. A UNICEF/WHO report cites, "the effects of the epidemic are starkly obvious from the banana plantations going fallow, the houses closed or abandoned, the funeral processions on the roads and the recent graves near homes where grandparents care for children whose parents have died."

Although, Uganda has launched a successful program designed to reduce the number of new infections, the country is left with millions of orphans.

However, Uganda is an example of a country that saw the enormity of the HIV/AIDS crisis and tried to take measures against it before it created a national disaster. In 1986, when the first cases of AIDS were identified in Uganda, the government launched a nationwide educational campaign. Using billboards and radio announcements, the government sought to educate the public about how AIDS was contracted and what could be done to prevent HIV infection. Over the past decade, the Ugandan anti-AIDS campaign has been credited with a 25 percent reduction rate in HIV infections in that country.

Currently, 10 percent of Uganda's population (approximately two million people) is HIV-positive. Although that is still a high number, it is better than some of its neighboring countries, where as many as one in eight adults are infected. Last year, in conjunction with the United States, Uganda became the first African country to begin AIDS vaccine trials. Also, in April 1999, Uganda joined four of its neighboring countries to form the Great Lakes Initiative which would be the first transnational program on HIV/AIDS prevention along the trade routes shared between those nations.

New vulnerable communities

There are areas of the world that, until recently, had been relatively protected from the spread of HIV/AIDS. The former Soviet Union and Eastern Europe had virtually no infections until approximately 1991. After the collapse of the Soviet Union, the former Soviet states became vulnerable to outside influences, including HIV/AIDS. The disease has spread through this part of the world mainly through unsafe drug practices, such as needle sharing. The poor economic condition of much of the former Soviet Union has contributed to a rise in drug use and prostitution. Contraception is largely unavailable or of poor quality, and the government lacks the money to provide education to the general public on HIV/AIDS. Also, as in many parts of the world, prostitutes feel that they are not in a position to force their clients to wear condoms. Currently in the Russian Federation it is believed that for every HIV-positive person who has been tested there are six other infected people who have not been tested.

Eastern Europe also has been hard hit by HIV/AIDS infections since the mid to late 1990s. Estimates for 1998 reported that approximately 190,000 Eastern European adults and children were living with the disease. This was a significant increase over the numbers predicted just one year earlier in 1997. Sharing contaminated needles has become the predominant means by which HIV/AIDS is spread in Eastern Europe.
HOW CAN WE HELP CHILDREN AFFECTED BY HIV/AIDS?

- International organizations that conduct research about HIV/AIDS should recognize that every person under age 18 is considered a child according to international standards.

Peer education may be one of best means for informing children and youth about HIV/AIDS.

Cooperation among health care professionals and joint HIV/AIDS research and projects should be encouraged across national borders.

There are numerous differences of opinion about how best to serve children's needs where HIV/AIDS is concerned. There are religious and philosophical differences, international and local differences, and conflicts between pharmaceutical and behavioral approaches.

For example, religious leaders in many parts of the world are opposed to sex education in schools, believing it corrupts children's moral upbringing. At the same time health care workers argue that providing education about HIV/AIDS in elementary schools is the most efficient way to reach the most children. According to health care workers and many AIDS activists, providing information about how the disease is transmitted and about its consequences would empower children to make educated choices about their behavior.

The conflicts between large-scale and local efforts designed to help children affected by HIV/AIDS also indicate that there is no singular approach to this problem. Although there are several international, regional and country-specific programs that have been created to deal with the increasing rates of HIV infection, many will ultimately fail. According to the UNDP, 2 most HIV/AIDS pro-

grams do not take into account the economic situation of the people most likely to become infected. Poorer people do not see the relevance of HIV/AIDS education programs on their lives when faced with more immediate problems like hunger. Also, there is the issue of translating information accurately in the local language and choosing media that work best in the context of the local culture.

Where monetary resources are small, leaders must make choices about whether it makes more sense to invest in education and prevention, or to invest in providing medical care and orphanages. Often, the cost of treating the opportunistic infections caused by AIDS is so expensive that it consumes a large amount of the total yearly health care budget in poorer countries.

Awareness and education

The mortality facts are clear—HIV/AIDS is deadly and there are long-term consequences for children and youth in every society. The challenge is making sure that children listen to accurate information and that they understand it. One means of providing this important information is through the use of peer educators (see the interview with Hydeia Broadbent on page 25).

To ensure accurate information is available about the impact the disease is having on children worldwide, a call must be placed to international organizations demanding that they create and maintain more carefully segregated databases on children. Data should reflect the world standard defining a child as a person under age 18 and shift away from identifying children as those under age 15. This will support a consistent approach to studying the impact of HIV/AIDS on children throughout the world. However, it is not enough just to educate children on how to protect themselves from this disease. Children live in dangerous situations that lead to exposure to HIV because of outside factors like economic conditions and prevailing social forces.

Prevention

Prevention programs are key to containing the spread of HIV/AIDS. However, prevention programs for a disease like HIV/AIDS
rarely work when handed down from international organizations. The best prevention programs come from within communities where there is a problem. Local prevention efforts are necessary, because communities are in a better position to judge what will work and what will not.

For example, in Senegal in 1987 there were 45 AIDS cases reported. The same year Ibrahima Ndoye, a gynecologist and expert in sexually transmitted diseases, initiated a country-wide AIDS education campaign with the help of Senegalese politicians and the religious community. Legislation was passed that required prostitutes to be screened every six months for HIV, receive free condoms and education. This law has helped keep the HIV-positive rate in Senegal from rising above 1.77 percent of the population. Both Catholic and Islamic religious leaders are participating in the educational campaign, even distributing condoms.

In the United States a needle exchange program in Baltimore, Maryland, is having success in decreasing the number of HIV infections caused by intravenous drug use. So far the program has enrolled 9,000 clients, exchanged 2.5 million needles and managed to send 1,000 users into drug treatment programs. One health official estimated that the $1.2 million dollars invested in the needle-exchange program has saved $30 million in medical costs that would have been incurred caring for clients who could have become HIV-positive.

Commitment to medical research

While the eradication of HIV/AIDS in the near future seems bleak, other diseases once thought to be unstoppable have been eradicated. Smallpox received its certification of global eradication in 1980, yet was once thought unstoppable. Experts are working to make the eradication of HIV/AIDS a possibility for the future, and advances in treatments are being made.

An increasing number of drugs are being approved for use in treating children with HIV/AIDS. The U. S. Food and Drug Administration (FDA) recently has approved Efavirenz, a once-a-day drug to fight AIDS. Also, in 1999, Nevirapine—when given to mothers during labor and to newborns—was discovered to be more

A Youth Living with AIDS
Works to Inform Peers about the Disease

Hydeia Broadbent is a 15-year-old girl living with AIDS in the United States. She was infected at birth by her biological mother who abandoned her. Although Hydeia suffered numerous illnesses as an infant, her HIV infection was not discovered until she was three—after being adopted by the Broadbent family. Hydeia provides a public service by talking with her peers about the disease. To continue this valuable work, her family and Clare Milligan of Montgomery, Alabama, have established the Hydeia L. Broadbent Foundation.

Hydeia: “Mom has always been very open with me about the disease. She told me that if people have problems with the fact that I have AIDS I should try to educate them about it. We have never kept it a secret.”

Hydeia’s mother, Patricia Broadbent: “After discovering that Hydeia was HIV-positive, we wondered what would happen. I was told Hydeia probably would live only to age five. We told her everything and began to learn about the disease. Hydeia knew all the aspects of AIDS. She knew how to protect others from herself. She and I decided to start an education campaign because there are teens in danger who don’t have the right information.”

YAP-I: What made you decide to go public and become an educator about AIDS?

Hydeia: “I want to tell kids about my situation. Kids react normally to me. I think I make them wake up and think about what they do before they do it. I emphasize that kids have choices about their actions, but there are consequences for some choices. I hope they choose safely because AIDS isn’t a fun disease to have.”
effective in reducing HIV transmission and less costly than AZT given in the same way. Nevirapine needs to be taken only once in a pill by the mother during labor and once in syrup form by the infant during the first three days of life. This new treatment costs approximately $4 for both mother and child. If administered properly and at the right time it could potentially prevent HIV infections in 300,000 to 400,000 infants each year.

Most HIV infection in children, worldwide, is transmitted through the mother during pregnancy or labor. Effective treatments are available to significantly decrease the chances of transmission of the disease from mother to child. By identifying and giving medical care to HIV-positive women during pregnancy children will benefit. Also, where safe alternatives to breastfeeding are available, HIV-positive women should be encouraged to use alternatives.

HIV/AIDS medicines often are not included in trade deals between poorer countries and those countries whose drug companies make the medications. These sorts of barriers should be removed in the interest of public health. Cooperation among health care professionals and joint HIV/AIDS research projects should be encouraged across national borders.

Care for the whole child

The UNDP has developed a program for children affected by HIV/AIDS containing five issue areas. First, children must be prepared for the future. It is unfair for children to watch their parents die without being told why and it is equally unfair that many parents refuse to acknowledge the fact that they are dying from AIDS and not create a plan for their children’s future care. Second, children are to be given any assistance they need after their parents have died. This insures that a child’s psychological and emotional needs are met. For example, UNICEF, Children in Need Network and Project Concern International have developed a program in Zambia which trains people in psychosocial counseling for orphans of the AIDS epidemic. Third, infected children whose parents have died as a result of HIV infection have special needs. A country’s laws on child protection must be enforced in this case. Fourth, the UNDP believes that vulnerable children, particularly those who have been turned out onto the street and young girls, need a greater amount of care. Finally, the main objective of the UNDP program is the reduction of adult infection rates in hopes of saving the future for their children.

Grassroots activists committed to children’s best interests can bring the recommendations made by UNDP into fruition. Until recently, U.S. children whose parents died of AIDS routinely entered the public system of foster care. However, the foster care system has not been equipped to deal with the growing AIDS orphan population, and foster families have not been adequately educated about HIV/AIDS nor allowed to make medical decisions for the children in their care. According to Mubarak Awad, Director of National Youth Advocate Program, it is possible and preferable to place children who are medically fragile, including HIV-positive children, in home-like settings instead of institutions. Foster parents who are given adequate training and have experience caring for an HIV-infected child show a willingness to open their homes to other infected children.

Experiencing first hand the lack of community support services in New York state, one grandmother caring for her granddaughter after her own daughter died of AIDS, founded an organization called Mothers of Children with AIDS (MOCA). MOCA was designed to offer a wide range of services to HIV-positive mothers concerned about where their children would go after they died. In response to the work of MOCA and other organizations like the Orphan Project, the state of New York adopted the Standby Guardian Act, which puts HIV/AIDS-affected children in the care of a person chosen by their afflicted parents. The act now serves as a model for other U.S. states.

Another example of people making international recommendations a reality occurred in the early 1990s when the Association Francois-Xavier Bagnoud (AFXB) created a house for abandoned HIV-positive children in Chiang-Mai in northern Thailand. Besides housing HIV-positive youth, AFXB had four other objectives: educate HIV-positive parents in order to stem the tide of abandonment, train medical personnel in the treatment of HIV-positive children, support research that benefits infected children, and work in collaborative efforts with other organizations. The
ultimate goal of the program is to reunite many of these children with their extended families.

CONCLUSION

Many have called the HIV/AIDS crisis a silent war against humanity. In this war it is clear that the most vulnerable members of society are children and youth—the group with the fastest growing rate of new HIV infections. They suffer when they are infected by the disease, and when they are orphaned or abandoned. Currently the children of African countries are bearing the brunt of the epidemic, however no country’s children are immune.

Although no cure for HIV/AIDS has been discovered, many things can be done to contain the epidemic and to increase the quality of life for those affected by it. Making medicines widely available and affordable, especially for children and pregnant women, is vital. Also important are prevention programs and providing accurate information about the nature of HIV/AIDS and how it is transmitted. Investing in the treatment and care of children affected by HIV/AIDS today is the most important means we have of stopping this epidemic in the future.

ENDNOTES

1. A retrovirus is any of a group of RNA-containing viruses (such as HIV) that produce reverse transcriptase by means of which DNA is produced using their RNA as a template and incorporated into the genome of infected cells and that include numerous tumorigenic viruses; on the WWW Webster Dictionary web site; available from http://www.m-w.com/cgi-bin/dictionary; Internet; accessed 23 September 1999.


3. According to data provided by World Health Organization (WHO), UNAIDS, and HIV INSITE of the University of California, San Francisco.


13. Ibid.

14. Ibid.

15. Ibid.


23. Ibid.

24. Ibid.


26. Ibid.


29. “Uganda: Deadly Traditions Persist,” USA Today, 23 May 1999, 8D.


34. Kent, “Care and Protection of Children and Young People Affected by AIDS.”


41. Ibid., 2.


44. Cohen, “Poverty and HIV/AIDS in Sub-Saharan Africa.”

45. The Ugandan government considers any child that has lost at least one parent to be an orphan.


49. Widjajanti, "HIV/AIDS on Children and Their Families."


58. Ibid.

59. Ibid.


63. Altman, "In Africa a Deadly Silence About AIDS Is Lifting."

64. HIV INSITE, "The Evolving Picture Region by Region."


67. HIV INSITE, "The Evolving Picture Region by Region."


71. 1998 World AIDS Campaign, "HIV Infection in Eastern Europe."


76. Stolberg, "The youngest faces of AIDS."

77. Altman, "New Means Found for Reducing HIV Transmission from Mother to Child."

78. Ibid.
Information and Book List

Forgotten Children of the AIDS Epidemic

Publications Available from UNAIDS:
20, Avenue Appia, CH-1211 Geneva 27, Switzerland
Tel: (41) 22 791 4765, Fax: (41) 22 791 4898
Email: unaidsoffice@unaidsoffice.org, Web site: www.unaidsoffice.org

UNAIDS World AIDS Campaign publications including—
“Challenges for Latin America and the Caribbean,” © 1999.

Publications Available from HIV INSITE: Gateway to AIDS Knowledge:
University of California—San Francisco
Positive Health Program, 3180 18th Street, #301
San Francisco, CA 94110 USA
Tel: (1) 415 476 7147, Fax: (1) 415 502 9556
Email: hivinsite@php.ucsf.edu, Web site: http://hivinsite.ucsf.edu


Publications Available from United Nations Development Programme (UNDP):
One United Nations Plaza, New York, NY 10017 USA
Tel: (1) 212 906 5315, Fax: (1) 212 906 5364
Email: hq@undp.org, Web site: http://www.undp.org


RESOURCE ORGANIZATIONS

UNAIDS
20, Avenue Appia
CH-1211 Geneva 27
Switzerland
Tel: (41) 22 791 4765
Fax: (41) 22 791 4898
Email: unaid@unaid.org
Web site: www.unaid.org

UNAIDS is the United Nations organization that was created to research the AIDS problem. The organization has a comprehensive web site with many accessible publications. It also is the sponsor of the World AIDS Day campaign.

World Health Organization (WHO)
Headquarters Office
20, Avenue Appia
CH-1211 Geneva 27
Switzerland
Telephone: (41) 22 791 21 11
Fax: (41) 22 791 0746
Email: info@who.ch
Web site: www.who.org

World Health Organization has the most up-to-date numbers on HIV/AIDS cases in the world. They publish findings both in hard copy and on the web. WHO has a searchable database with downloadable materials.

HIV INSITE does work on international and national AIDS research. The organization has a searchable web site and many documents on the global epidemic to download.

Centers for Disease Control and Prevention (CDC)
1400 I Street, NW
Suite 1125
Washington, DC 20005 USA
Tel: (1) 800 394 1945
Fax: (1) 202 210 0923
Email: info@cdc.org
Web site: www.cdc.gov

A section of the United States Department of Health and Human Services, CDC studies and disseminates information on a variety of health issues. The organization has a searchable database with downloadable reports.

United Nations Development Programme (UNDP)
One United Nations Plaza
New York, NY 10017 USA
Tel: (1) 212 906 5315
Fax: (1) 212 906 5364
Email: hq@undp.org
Web site: www.undp.org

The UNDP helps nations in their efforts to achieve sustainable human development. Their web site is comprehensive and contains downloadable materials on a variety of topics.
UNICEF
3 UN Plaza
New York, NY 10017 USA
Tel: (1) 212 326 7000
Fax: (1) 212 887 7465
Email: nwtmaster@unicef.org
Web site: www.unicef.org

UNICEF is a partner organization in UNAIDS. The organization also provides general and country-specific information as well as a searchable database.

Save the Children, UK
17 Grove Lane
London SE5 8RD
United Kingdom
Tel: (44) 171 703 5400
Fax: (44) 171 703 2276
Web site: www.save.org.uk

General information and publications are available on the Save the Children web site. The web site also contains a searchable database.

UN Foundation
1301 Connecticut Avenue, NW
Suite 700
Washington, D.C. 20036, USA
Tel: (1) 202 887-9040
Fax: (1) 202 887-9021
Web site: www.unfoundation.org

UN Foundation has a searchable web site with an extensive archive of international news-clippings on a wide variety of topics. The organization gives daily updates to subscribers.

Hydeia L. Broadbent Foundation (HLBF)
1425 N. Sierra Bonita Avenue
Suite 411
Los Angeles, CA 90046-4198
Tel: (1) 323 874-0883
Fax: (1) 323 874-0388
Email: hydeia@pacificbell.net

Founded in 1993, the Hydeia L. Broadbent Foundation seeks to provide HIV/AIDS prevention and health education programs to youth, in order to reinforce safe behaviors.

The Ark Foundation of Africa
1505 North Capital St., NW
Washington, DC 20002-3343
Tel: (1) 202 332-5420
Fax: (1) 202 656 6244
Email: rkaime@hotmail.com

The Ark Foundation of Africa sponsors educational programs in East Africa on HIV/AIDS prevention. Their HIV outreach programs feature peer educators using the performing arts to teach about HIV/AIDS.

"Helping kids understand about AIDS is the most important thing I do. Some kids like to pretend that it's not happening in their world. By letting them know what's really going on, I might save someone's life."

—Hydeia L. Broadbent
15-year-old AIDS patient & activist

$6.00US
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4545 42nd St., NW, Suite 209
Washington, DC 20016 USA