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World AIDS Campaign with Children and Young People

Children and HIV/AIDS

UNAIDS Briefing Paper


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Children and HIV/AIDS

From the sick and neglected infants dying of AIDS in the orphanages of Ceaucescu’s Romania to the young people watching over their dying parents in East Africa, images of the children of the AIDS epidemic have been among the most compelling reminders of the reach of this global crisis.

Today’s children — defined by the United Nations Convention on the Rights of the Child as people below the age of 18 years — are growing up in a world with AIDS. They are having to cope not only with issues and problems that have long existed and are now being revealed by the HIV/AIDS epidemic, but also with those that result directly from the epidemic and which, until recently, people only had to face as adults.

More children are contracting HIV than ever before, and there is no sign that the infection rate is slowing.

Children below the age of 18 are vulnerable to infection through mother-to-child transmission, unsafe blood and injection practices, sex — including sexual abuse, coercion and commercial exploitation — and injecting drug use. Much of this vulnerability stems from failure to respect their rights, including those guaranteed under the United Nations Convention on the Rights of the Child.

Unfortunately, the magnitude of the problem remains to be documented with any precision. There is a glaring gap in data on the incidence of infection among children as they grow into adolescence.

One of the shortcomings of HIV epidemiological surveillance to date has been to use the cut-off point of 14 years for younger children in the collection and aggregation of data — the older 15-49 year age group being considered as adults. A first step therefore in governments in fulfilling their obligations to children in the context of HIV/AIDS is to collect comprehensive data on HIV transmission among older children and adolescents, so that they can design effective prevention and care programmes in the light of these data.

The number of children infected around birth is easier to estimate. Around 90% of children who become infected under the age of 15 years acquire the virus from their HIV-infected mothers, whether before or during birth or through breastfeeding. And as women of childbearing age themselves become infected in ever greater numbers — a trend reflecting their own social vulnerability to HIV — the number of babies infected through mother-to-child transmission rises correspondingly.

Since the beginning of the HIV/AIDS epidemic in the late 1970s and early 1980s, UNAIDS and WHO estimate that more than 4 million children under the age of 15 years have been infected with HIV. In 1998 alone, around 1400 children died of AIDS daily and an even larger number became newly infected with each passing day. At the end of that year, it was estimated that 1.2 million children under 15 were living with the virus. Well over 90% of these children live in developing countries.

In sub-Saharan Africa, the region most severely affected by AIDS so far, the US Bureau of the Census has predicted that AIDS will offset improvements in infant and child mortality achieved in the past decade. By the year 2010, if the spread of HIV is not contained, AIDS may increase infant mortality by as much as 75% and under-five child mortality by more than 100% in those regions most affected by the disease.

Children are not only infected by HIV, they are also affected. While the number of those infected by HIV continues to grow, the epidemic is also having a direct and devastating effect on millions of other children whose lives have been permanently altered by the intrusion of HIV/AIDS into their households or communities.

Children living in hard-hit communities feel the impact as they lose parents, teachers and caregivers to AIDS, as health systems are stretched beyond their limits, and as their families take in other children who have been orphaned by the epidemic.
Individual households struck by AIDS often suffer disproportionately from stigma, isolation and impoverishment, and the emotional toll on the children is heavier still. As the number of children orphaned or otherwise affected by AIDS rises, social security systems, already underfunded and overburdened where they exist, reach breaking point. The impact is most acute on girls and boys already facing hardship or neglect — children in institutional care, children in poor neighbourhoods or slum areas, refugee children — and even more so for young girls who have unequal opportunities for schooling and employment.

In countries such as Uganda, where the epidemic already took hold over a decade ago, the impact of AIDS on the socioeconomic fabric of communities is becoming increasingly visible. As one UNICEF/WHO report puts it, “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.” AIDS sets back development and changes patterns of life. To a child, this translates into a world turned upside down.

But the shadow of the epidemic extends far beyond even these millions of infected and affected children. In the final analysis, all children of the world henceforth face a lifetime of risk from HIV. They are exposed to the risk of HIV infection at different life stages as they grow into adulthood, because of circumstances such as sexual exploitation and abuse, or simply due to violation of their rights to information, to education and services. There is a need for greater recognition of the specific requirements of girls and of especially vulnerable children, both boys and girls, such as refugees, street kids, and children exposed to drug use.

In short, children and young people in all countries, and those who care for and are responsible for them, are having to adjust and adapt to this new world. The global epidemic is continuing to accelerate. There is, as yet, no vaccine against the virus. Neither is there a cure. For all the welcome recent advances in scientific treatments, there also remains great uncertainty as to whether and how such treatments could ever be made accessible to the vast majority of people living with HIV who are in the developing world.

AIDS has changed the world for children. The United Nations Convention on the Rights of the Child provides a framework for promoting and protecting the rights of children which can minimize the impact of the HIV/AIDS epidemic on them. Yet, despite almost universal ratification, the response to infected, affected and vulnerable children has remained inconsistent. Internationally, AIDS programmes for children have been ad hoc and fragmented and have lagged behind those for adults. In many developing countries, this situation is worsened by poverty and other factors, such as wars and the resulting social breakdown of many communities.

The industrialized world has unmet needs as well. In a survey conducted in 1992 in the United States, government lobbyists on children’s issues admitted that while they were generally successful in promoting other causes such as education and anti-poverty programmes, they were much less so with childhood AIDS issues such as prevention, orphan care and education around sexual health.

In a world with AIDS, children must become everybody’s responsibility.

On World AIDS Day 1994, heads of government from 42 countries attending the Paris AIDS Summit called for a global partnership to reduce the impact of the HIV/AIDS epidemic on children and young people.

This briefing summarizes how the epidemic is having an impact on children who are infected by HIV, on those who are directly affected by HIV/AIDS in their families or communities, and on children who are at risk of HIV infection. It outlines the global and national action needed to support children and their families as they face life in a world with AIDS.
The Rights of the Child in the context of HIV/AIDS

All children under the age of 18 living in today’s world — whether they are themselves infected with HIV, affected by AIDS in their households or communities, or living in the shadow of HIV risk — are recognized by the United Nations Convention on the Rights of the Child.

In the context of HIV/AIDS, the United Nations Convention on the Rights of the Child has spelled out principles for reducing children’s vulnerability to infection and to protect children from discrimination because of their real or perceived HIV/AIDS status. This human rights framework can be used by governments to ensure that the best interests of children with regard to HIV/AIDS are promoted and addressed.

- Children’s right to life, survival and development should be guaranteed.
- The civil rights and freedoms of children should be respected, with emphasis on removing policies which may result in children being separated from their parents or families.
- Children should have access to HIV/AIDS prevention education, information, and to the means of prevention. Measures should be taken to remove social, cultural, political or religious barriers that block children’s access to these.
- Children’s right to confidentiality and privacy in regard to their HIV status should be recognized. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved, which should be obtained in the context of pre-test counselling. If children’s legal guardians are involved, they should pay due regard to the child’s view, if the child is of an age or maturity to have such views.
- All children should receive adequate treatment and care for HIV/AIDS, including those children for whom this may require additional costs because of their circumstances, such as orphans.
- States should include HIV/AIDS as a disability, if disability laws exist, to strengthen the protection of people living with HIV/AIDS against discrimination.
- Children should have access to health care services and programmes, and barriers to access encountered by especially vulnerable groups should be removed.
- Children should have access to social benefits, including social security and social insurance.
- Children should enjoy adequate standards of living.
- Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.
- No discrimination should be suffered by children in leisure, recreational, sport, and cultural activities because of their HIV/AIDS status.
- Special measures should be taken by governments to prevent and minimize the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.

Children and HIV/AIDS

Children with HIV: A future compromised

HIV/AIDS is a disease of the young. Last year altogether 590,000 children under the age of 15 years became infected with HIV worldwide, bringing the total number of children living with the virus at the end of 1998 to 1.2 million. Hundreds of thousands of HIV-infected babies are born every year to HIV-positive mothers.

In 1998 alone, of the 2.5 million people who died of AIDS, 510,000 were children under 15. Health services, already under strain in many developing countries and in poorer areas of the industrialized world, are likely to have to care for increasing numbers of children with severe HIV-associated illnesses.

Children with HIV/AIDS in developing countries

HIV infection in children typically runs a faster course to AIDS and then death than in adults. And paediatric AIDS kills especially fast in developing countries. Sick children in developing countries are generally at greater risk of death than children in industrialized countries and this is no less true of children with HIV. In Europe, 80% of HIV-infected children survive at least until their third birthday, and more than 20% reach the age of 10. In Zambian, however, nearly half of HIV-infected children in one study had died by the age of two. In another study in Uganda, 66% were dead by the age of three.

In Africa, in general, the situation for sick HIV-positive children is very grave. Many of the common, inexpensive antibiotics and other medications used to treat sick children without HIV also work for children with HIV – but often, even these drugs are unavailable. Poor families are less able to afford health care and basic drugs to tackle opportunistic infections, a problem which is even more acute in countries with low health budgets and where health services are difficult to access. In addition, drugs for the rarer HIV-associated illnesses have not been part of essential drug programmes that supply the world’s poorest hospitals and clinics, and clinical practice guidelines for paediatric AIDS are often less clear than those for adults. Increasing the availability of basic antibiotics for acute respiratory infections, of antifungal drugs for thrush and cryptococcal meningitis (a severe infection of the nervous system), and of drugs that can cure tuberculosis is an urgent priority for developing countries with children and adults affected by AIDS. UNAIDS has made greater access to these drugs one of its primary concerns.

However, the more rapid course of paediatric AIDS in Africa is explained not only by less developed health care systems, but also by poor nutrition and widespread infectious diseases to which children are particularly vulnerable.

Poverty is a key reason why children die more quickly of AIDS in developing countries. If children are sleeping three or four to a room, for example, which is more common in poorer households, they are far more likely to transmit and contract tuberculosis or other respiratory diseases if one of them has any of these infections. If children are poorly nourished, their immune systems will weaken. If families do not have access to clean water, they are more vulnerable to waterborne diseases including diarrhoea.

Children with HIV commonly experience wasting and delayed development and are often killed by typical childhood diseases like diarrhoea, measles, tuberculosis and other respiratory infections. Because these diseases are often the same as those that kill other children, it is sometimes difficult for health workers in poor countries, without access to expensive HIV testing equipment, to distinguish HIV-positive children from others. This may have at least two important consequences. First, children with HIV may not receive the special care they need. Secondly, a general apathy about child health may arise, with consequences for all children. In communities around the world, increases in infant and child deaths due to AIDS may lead to a mistaken belief that immunization and nutrition programmes for children do not work. Disenchantment with these programmes could increase mortality in uninfected children.
Women and children — a dual vulnerability

During 1998, 5.2 million adults became infected with HIV, nearly half of them women.

Women of childbearing age make up an ever-increasing proportion of people with HIV worldwide — a trend that reflects their own biological and social vulnerability to infection. Long-standing legal, economic and societal manifestations of gender discrimination and inattention to their sexual health influence women’s vulnerability to HIV considerably.

In Kenya, for example, an AIDS CAP report found that the vulnerability of women is exacerbated by historical trends which have removed men from their families for lengthy periods of time, increased the acceptability of male sexual activity outside of marital relations, and sanctioned the behaviour of older men to use their wealth and prestige to seek sex with girls and young women.

In the longer term, therefore, reducing the vulnerability of infants to infection with HIV demands the same kind of action as reducing the magnitude of sexual transmission to women. The human rights of women must be fully promoted and protected. This approach was reinforced by both the International Conference on Population and Development held in Cairo in 1994 and the United Nations Fourth World Conference on Women, held in Beijing in 1995, which called for gender-sensitive initiatives to address HIV/AIDS and to end the social subordination of women and girls. Such an approach encompasses the ability of all women, whether or not infected with HIV, to make and carry out decisions about their reproductive and sexual health, including the avoidance of unwanted and/or unwanted pregnancies.

In the immediate, it is also vital to increase women’s access to information about the prevention of HIV transmission in general and, within this, about existing ways of diminishing the risk of mother-to-child transmission. But for prevention strategies to be equitable and effective, AIDS programmes must avoid falling into the ancient trap of seeing women only as mothers. It would be tragic if, once again, as for contraception, women alone were left with the responsibility for HIV prevention within sexual relationships, and men were absolved of this responsibility.

HIV prevention must also move beyond measures that focus narrowly on reducing the transmission of HIV between sexual partners. As stressed by UNFPA and other leading agencies, the respective status and roles of men and women in society must be considered in order to understand and act on the constraints imposed by the gender gap on behaviours relevant to HIV.

The dominant mode of transmission of HIV to newborn babies is so-called mother-to-child transmission (also known as vertical or perinatal transmission). While in poorer countries some babies are still being infected through contaminated blood or medical equipment, virtually all HIV-infected infants have acquired the virus from their HIV-positive mothers during pregnancy, labour or delivery, or acquired it after birth through breastfeeding. Of the more than 4 million infants and children under 15 years infected with HIV since the beginning of the pandemic, over 90% acquired the virus through this route.

At least 95% of all infants infected through mother-to-child transmission live in a developing country. Most live in sub-Saharan Africa. However, the number of cases in India and South-East Asia appears to be rising rapidly.

While not all children born to HIV-positive mothers become infected, this risk is, again, significantly greater in poorer countries. Most studies suggest that in the absence of preventive measures, the probability that an HIV-positive woman’s baby will be infected ranges from 25% to 35% in developing countries, where breastfeeding is the norm, and from 15% to 25% in industrialized countries.

There are a number of factors that increase a woman’s risk of having an infected baby. They include a depressed immune status, poor nutrition, complications during pregnancy, and protracted labour after the waters break.

A major risk factor for the baby is breastfeeding — a practice that by and large is the norm in developing countries. It is estimated that in populations where breastfeeding is the norm it may account for more than one-third of all infections transmitted from mother to child. But while breastfeeding can kill by transmitting HIV, bottle-feeding can also be dangerous and increases risks to child health. In recent years, breastfeeding has been heavily
promoted and encouraged for good reason. It affords vital protection against deadly childhood diseases, particularly diarrhea and respiratory infections. And breastfeeding is a natural, cost-free method, whereas the cost of infant formula and even the clean water and fuel needed to prepare it are often beyond the means of poor families in developing countries.

Mothers of a newborn who know they have HIV thus face a difficult dilemma in choosing between breastfeeding and bottle-feeding. The context will differ depending on the country and the woman’s own socioeconomic status. For example, in Thailand where there is relatively wide access to safe water, HIV-positive mothers are being given free infant formula by the government and provided with information on the risk factors, and are encouraged to opt for this replacement feeding. In countries in sub-Saharan Africa, however, providing infant formula would not be appropriate in many settings because clean water for making up the formula is not available. In many places, realistic and sustainable options may eventually include wet-nursing by relatives who have been tested and are HIV-negative, and the use of home-prepared formula made from animal milks, typically from cows, goats, buffaloes or sheep. The composition of animal milks is different from that of human milk, and they may lack micronutrients, especially iron, so they would need to be modified for infants according to nutritionally approved recipes.

Given the importance of breastfeeding to infant health, but recognizing the part breast milk plays in mother-to-child transmission, UNAIDS, UNICEF and WHO recommend that appropriate alternatives to breastfeeding be made available and affordable for women whom testing has shown to be HIV-positive, while efforts to protect, promote and support breastfeeding by women who are HIV-negative or of unknown HIV status be strengthened.

**Anti-HIV drugs to keep babies from getting infected**

The policy of UNAIDS and its cosponsors is to encourage HIV-positive mothers to be given as much information as possible on the relative risks of breastfeeding and alternative feeding methods so that they can decide whether to breastfeed or not or whether to shorten the breastfeeding period. Women must decide for themselves how to handle the delicate balance between the risks and advantages of the various approaches — there can be no universally valid recommendation. But only women in possession of all the information are in a position to make fully informed choices; this information includes knowing whether one is infected or not, which requires that voluntary HIV testing and counselling facilities be available.

In 1994, French and American researchers found that a two-month course of the antiviral drug AZT (zidovudine) administered to HIV-positive women in pregnancy, during labour and delivery, and after birth to their newborns reduced the rate of mother-to-child transmission by two-thirds in the absence of breastfeeding. This was clearly an important breakthrough, and in many industrialized countries including the United Kingdom and the United States, and in countries such as Brazil, the initial AZT regimen is now routinely offered to HIV-positive pregnant women and their newborns.

However, it soon became clear that this preventive regimen would be difficult if not impossible to apply in many developing country settings. To begin with, AZT is a very expensive drug. A full course of preventive treatment for a pregnant woman and her newborn costs about US$1000 per pregnancy in the United States. An equally important problem is that the AZT regimen as initially developed calls for the drug to be given for several months before delivery, and to be administered as an intravenous infusion during delivery. In many developing countries, where the annual per capita health expenditure may be as little as US$10, and where women often attend clinics for prenatal care late in pregnancy if at all, AZT is only available to the very wealthy. UNAIDS therefore promoted and supported research to find alternative drug regimens that would better suit the circumstances of women in the developing world.

A trial concluded in Thailand in February 1998 showed that a short regimen of zidovudine pills given during the last weeks of pregnancy cuts the rate of mother-to-child transmission by half, at less than a tenth of the cost of the longer course. Because the women were also given safe alternatives to breastfeeding, overall transmission to the infants in the study population was reduced to 9%, compared with the norm in developing countries.
of 25% to 35%. Other research is in progress to develop still shorter regimens, including a regimen which could be used even for women who do not come for care before they enter labour. In addition, researchers are still looking into the question of whether some regimens might be helpful for reducing transmission to infants that are breastfed.

UNAIDS together with WHO and UNICEF, has launched an initiative in 11 pilot countries to reduce HIV transmission from mother to child in low-income countries and increase HIV-positive mothers’ chances of having healthy children. The initiative seeks to support approximately 30,000 HIV-positive women. It has six components: early access to adequate antenatal care, voluntary and confidential counseling and HIV testing for women and their partners, antiretrovirals before and after pregnancy and delivery for HIV-positive women and their newborns, improved care during labour and delivery, counselling for HIV-positive women explaining a range of choices for infant feeding, and support for HIV-positive women who choose not to breastfeed.

At the same time, every effort must be made to ensure that women are counselled and supported in refusing unsafe sex during pregnancy — for their own sake, to maximize their chances of staying uninfected, and for the sake of protecting their infants. It is equally important to recognize and promote male responsibility in this respect.

To increase women’s control over the situation, it is important for countries to make voluntary HIV testing and counselling more widely available. As preventive interventions become more widespread, HIV-infected women would have to know their HIV status in order to benefit from them. Whether such services are made available in general or within prenatal programmes, they should include confidentiality, referral to psychological support, and care services for HIV-positive women who may face abandonment by their family and community ostracism. Even in the absence of therapeutic interventions, voluntary counselling and testing offers benefits for HIV-positive women, men and their sex partners. It permits them to make informed decisions regarding sexual activity, contraception, termination of pregnancy (where legally available) and methods of infant feeding, and gives them the opportunity of seeking early access to care.

It is not just mother-to-child

- About 10% of HIV-positive children under age 15 become infected through routes other than mother-to-child transmission.
- Some children acquire HIV from blood products containing HIV or from contact with unsterile skin-piercing instruments.

In Western Europe and the United States, a large number of children with haemophilia, a blood-clotting disorder that affects mainly males, were infected through blood products in the early 1980s. Although medical practices and blood supplies have since been improved in these and many other countries, elsewhere the dangers of transmission through unsafe blood and contaminated injection equipment in hospitals and other medical settings persist. The risk of contracting HIV infection through a blood transfusion is particularly great for children living in countries where the blood supply is not properly screened for HIV.

Adolescents are particularly vulnerable to HIV infection through injecting drug use and, above all, through sex. Issues regarding these children at risk are described in a later section of this report.
Children orphaned by AIDS

No one knows exactly how many children have been orphaned by AIDS worldwide, but UNAIDS estimates that, between the beginning of the epidemic and the end of 1997, 8.2 million children had lost their mothers to AIDS before they turned 15; more than 90% of them lived in a sub-Saharan African country. At the end of 1997, there were around 6.2 million such orphans under age 15 struggling to survive without their mother, and often without their father too.

While the cumulative figure of 8.2 million orphans is appalling, it reflects only a tiny part of a far larger tragedy. Children whose mother, or both of whose parents, have HIV begin to experience loss and suffering long before their parents’ death. In any given country, the number of children with an infected parent is far greater than the number of children who have already lost a parent to AIDS. Children orphaned by AIDS are just the most visible part, the tip of the iceberg, of the larger looming concerns over children who have a parent living with HIV/AIDS.

Most children orphaned by AIDS are concentrated in those countries most severely affected by the epidemic. UNAIDS estimates that by the end of 1997, 1.1 million Ugandan children under the age of 15 had lost at least one parent to AIDS.

According to UNICEF, children orphaned by AIDS in Zimbabwe are the largest and fastest growing category of children in difficult circumstances. UNAIDS estimates that by 1997, approximately 8% of children under 15 had lost their mothers to AIDS.

A uniquely painful experience

Children who lose a parent to AIDS suffer grief and confusion, like any other children who experience the death of a parent. But there are special differences.

For one thing, the psychological impact can be even more intense than for children whose parents die from more sudden causes, such as in armed conflict or as a result of an accident. HIV ultimately makes people ill but it runs an unpredictable course. There are typically months or years of stress, suffering or depression before a parent dies. And in developing countries, where the epidemic is concentrated, effective pain or symptom relief is often unavailable to alleviate a parent’s suffering.

The children’s distress is often compounded by the prejudice and social exclusion directed at individuals with HIV and their families. This stigma may translate into denial of access to schooling and health care and into a violation of the inheritance rights of orphaned children. In this respect, girls may be at a further disadvantage.

A final cruel difference from other parental diseases is that HIV may well have spread sexually between the father and mother. Thus the child’s chances of losing a second parent relatively quickly are far higher than, say, those of a child who has lost a parent to accidental death or to a non-infectious disease.

The uniquely painful features of parental HIV/AIDS are of course of deep concern to adults themselves. For HIV-positive mothers and father, making provision for their families is a main priority when they learn that they are infected. “My biggest fear was what was going to happen to the children”, says Major Rurungga Rubamira, a major in the Ugandan army and the founder of the Ugandan National Association of People Living with HIV/AIDS. “I didn’t know how long I was going to live and I still felt that within the time left I must try to do something. I tried to start some kind of business for my wife and I tried also to put up a house.”

Extended families soak up the pressure — but for how long?

The extended family is the traditional social security system in many countries. In many developing countries, deep-rooted kinship systems have accordingly provided support to children and families affected by AIDS. It is common, for example, for orphaned children to be taken in by aunts and uncles or even grandparents, who may have little income and who may even have been counting on being supported...
by the very son or daughter who died of AIDS.

The remarkable generosity of many people in countries most affected by AIDS is also shown by the high incidence of fostering of orphans by unrelated families, often by neighbours. A study in Kagera, Tanzania, indicated that families who had themselves experienced an AIDS death were more likely to take in AIDS orphans from other households. Those households with the most dependents were also the most willing to take on additional orphans.

Financial pressures on those least able to afford them have inevitably increased. “I have 11 orphans living with me”, says Leone Navalraka from Uganda. “My elder sister died and left me with her six children. And the other five belong to my daughter who also passed away. Taking care of these children is a real burden,” she says.

Even before the AIDS epidemic, many of these communities were already being pushed to breaking point as a result of labour migration, demographic change and other factors. With the advent of AIDS, the constraints have become even greater. One of the symptoms of this is the increasing number of households now headed by children and young people – households which may previously have been headed by grandparents at the death of the parents. “The death of a grandparent may leave a situation where there is nobody else in the extended family willing to care for the children, giving rise to orphan households headed by older siblings”, says Geoff Foster of the Family AIDS Caring Trust in Zimbabwe.

It is not only in developing countries that the extended family system is under strain. “Many European countries, particularly in Central and Eastern Europe, are experiencing problems as family systems come under pressure because of changing social structures and demography”, argues Naomi Honigsbam of the European Forum on HIV/AIDS, Children and Families. The same is increasingly true, for example, in metropolitan areas of the United States, such as New Haven and New York.

A vicious circle of poverty and discrimination

The relation between HIV/AIDS, impoverishment and denial of human rights is apparent in the impact of the epidemic on children who have been orphaned by AIDS.

When an HIV diagnosis in the family becomes known, friends may come to visit less often, and children may be taunted or harassed by schoolmates. In Zimbabwe, focus group discussions with members of AIDS-affected communities indicated that the social isolation of children orphaned by AIDS was common.

And in the north of Thailand, a 1994 study of 116 households affected by HIV found that stigmatization, due largely to incorrect beliefs about HIV transmission, was widespread in everyday life. It was acknowledged by 20% of such households that other children in the area were forbidden to play with children from HIV-affected families.

Family poverty can follow in the footsteps of stigmatization.

The Thai study found that as a result of AIDS many parents had lost jobs and family enterprises had lost customers.

Many extended families that have accepted orphans cannot afford to send all their children to school, and orphans are often the first to be denied education. “My foster mother wants to stop me from going to school. She wants me to work as a maid so I can earn money to buy food”, says Beatrice, a 16-year-old from Kenya. A study in Zambia indicated that in urban areas, 32% of orphans were not enrolled in school, compared with 25% of non-orphans. In rural areas, 68% of orphans were not enrolled compared with 48% of non-orphans.

For many families, sending their children to school simply becomes an impossible option. “When my father died I was 14 years old”, says Maurice Kibua, from Uganda. “There were eight of us and my mother was left in care of us. I became the head of the family and I was responsible for looking for money, food, clothing, and even shelter... I had no choice but to drop out of school.”

Discrimination in accessing health care is a major form of social exclusion faced by people infected or affected, including orphans. About two-thirds of children born to HIV-positive mothers do not contract the infection and grow up to be as healthy as any other child in the community. However, this fact is often unknown or ignored. Evidence suggests that AIDS orphans may be at greater risk of dying of preventable diseases and infections because of the mistaken belief that when they become ill it must be due to AIDS and therefore
there is no point in seeking medical help.

Children orphaned by AIDS are also at risk of losing their property rights, and rights to inheritance. Moreover, as shown before, the realization of children’s rights is inextricably linked with their mothers’ human rights—hence laws which disenfranchise widows have a devastating effect on the lives of their children.

The resulting poverty and isolation can create a vicious circle, placing AIDS orphans, and particularly orphaned girls, at greater risk of contracting HIV themselves.

“This lady likes mistreating me because my mother is dead”, says one Ugandan girl interviewed by Pano. “She wants me to sleep with men because I stay at her house. She brings these men into her house and introduces me to them. She often tells me to be good to them and says this the only way I can continue to live in her house.”

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<th>What is being done to help?</th>
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The problems faced by HIV-affected families have become a major priority for many national aid programmes, as well as for international organizations such as UNICEF and the Save the Children Fund. There are thousands of small community-based schemes around the world that aim to provide care and support to children orphaned by AIDS. In Uganda, for example, an organization called Uweso provides emergency material support and vocational training for these orphans. In Côte d’Ivoire, the International Catholic Child Bureau is helping to place orphans in foster homes and provides training and assistance. In Kenya and Tanzania, the African Development Foundation has funded farm projects, secondary education and housing for AIDS-affected families.

But such projects are not being carried out on the scale that is required. Most orphan programmes can only help fewer than a hundred children at one time. In countries like Thailand, Uganda and Zambia where tens or hundreds of thousands of children are affected, the response desperately needs to be geared up to provide even basic support to those who most need it.

Finance is an important consideration. Many such programmes rely on funding from non-governmental organizations based in economically affluent countries and UN agencies, and are seldom self-sustaining. Investment in AIDS-affected children is necessary for a stable future, both for the children themselves and for their communities. But in the world’s poorest countries, children orphaned by AIDS may be seen as only one of many competing urgent priorities.

Despite a widespread belief that orphans are well-served by AIDS care organizations, there is a growing realization that such care is inadequate and that children orphaned by AIDS are a neglected group.

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<th>Reaching children before their parents die</th>
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Problems for children affected by HIV are most acute from the time that infection is diagnosed in a parent. If organizations wait until children become orphans, it is almost too late. Before the massacres in Rwanda in 1994, Caritas Rwanda, an NGO, tried to help parents plan for the future of their children. They worked with parents to identify solutions and arrange for children to move in with relatives or foster parents. Caritas also advised parents on legal and property matters.

In 1994, representatives from NGOs throughout southern and East Africa drew up the “Lusaka Declaration on Support to Children and Families affected by AIDS”. It urged that wherever possible, efforts should be made to keep children of AIDS-affected families in their communities. These efforts, it argued, should begin before the death of the parent. Home-based care schemes, in which visiting health or community support teams attend AIDS patients at home, should also be involved in helping parents plan ahead for their children.

The declaration also recognized that families affected by HIV/AIDS are vulnerable to exploitation and recommended that NGOs inform people affected by HIV/AIDS of their legal rights, and that governments revise existing laws to further protect these individuals.

Orphanages should only be considered as a last resort in providing care to those orphaned by AIDS, according to experts. Orphanages are far more expensive than community-based approaches and they can be culturally inappropriate if they cut children off from their social origins. The link between generations is very important.
Children in the shadow of HIV risk

In a world with AIDS, there are children who are infected with HIV and those who are affected by the epidemic’s intrusion into their families or communities. But the epidemic casts its biggest shadow by far on the hundreds of millions of children who live in risk of HIV infection — either because their fundamental rights, including the right to health care and to HIV information and education, are ignored, or because their personal or societal circumstances make them especially vulnerable.

**HIV and child sexual abuse**

Sexual abuse during childhood and adolescence, while not a new phenomenon, has recently emerged as a pervasive problem affecting all societies.

Sexual abuse of children takes two main forms — commercial sexual exploitation, which is now known to be a multi-billion dollar world industry, and sexual abuse in the home or community, whether by relatives, “friends” or associates of the child’s family, or others with easy access to the child, such as schoolteachers or employers. Whatever its form, such abuse usually leaves serious psychological damage in its wake.

**Children in the sex trade**

No one knows how many child sex workers there are in the world. Because of the clandestine nature of the trade, precise figures are not known, and there is a chronic lack of accurate research in this area. Figures reported to the first World Congress Against Commercial Sexual Exploitation of Children, which took place in Stockholm in August 1996, suggested that:

- worldwide, more than a million children enter the sex trade every year;
- children are working as prostitutes in Europe;
- there are between 400 000 and 500 000 child prostitutes in India, according to a survey by India Today magazine;
- around 25 400 minors are engaged in prostitution in the Dominican Republic, according to a survey there.

What research has been done suggests that such exploitation is growing, and the age of the children involved is falling. Most children in the sex industry are girls aged between 13 and 18, although there are instances of much younger children being sold. Many such children spend most of their lives on the street, often because they are escaping violence or sexual abuse at home. Other children live in brothels, having been drawn into prostitution by procurers. For example, female children are often purchased from their parents or lured to the city with promises of jobs, education or money, only to be sold to a pimp.

Girls are at greater risk than boys because of systematic gender discrimination resulting in lack of access to educational and employment opportunities. Those who have been abused or forced into prostitution are often stigmatized and marginalized, which further undermines their status, and reduces their opportunities for accessing education, formal employment and, in many societies, marriage.

The HIV/AIDS epidemic has made child sexual abuse and child prostitution more dangerous than ever before. Studies everywhere indicate that rates of HIV infection among child sex workers and street children are often very high. Surveys of Kenyan girls living on the street indicated that as many as 30% were HIV-positive.

The belief that children are less likely to be infected has raised the demand for younger sex workers in recent years. The vulnerability of children to sexual exploitation, either through sex work or abuse, may well result in their becoming infected with other sexually transmitted diseases such as gonorrhea, syphilis and chancroid. By damaging the surfaces of the reproductive tract, physical trauma and sexually transmitted disease each increase the child’s susceptibility to HIV as well as the HIV/STD risk to their clients. The problem is compounded by the lack of health care services meeting the sexual and reproductive health needs of children.
Only recently has a strong activist movement, driven primarily by non-governmental child action groups, brought the commercial sexual exploitation of children to international attention. The 1996 Stockholm World Congress Against Commercial Sexual Exploitation of Children marked the first concerted international attempt to tackle the problem.

Steps are being taken at national levels to target commercial sexual exploitation not only at home but also abroad. New extra-territorial laws in some countries, including Australia, Germany, Japan, the Netherlands, Sweden, the United States and the United Kingdom, now permit countries to prosecute nationals guilty of sex offences against children overseas. The World Trade Organization recently established a new Task Force to target tour operators and hotels that knowingly cater to sex tourists. Enforcing these new sanctions and laws will require international cooperation from a variety of actors including government entities such as the police and judicial systems, as well as NGOs.

However, several experts at the Stockholm conference also stressed that, while sex tourism is a major problem and was well documented, “commercial sexual exploitation of children is predominantly a local issue, with both clients and agents coming from the local community.”

Whether the exploiters are local or foreign, punishment is necessary — but not sufficient. There is an urgent need to campaign for a change in the sexual attitudes and behaviour of adults.

Abuse closer to home

Awareness of the scale of child abuse which takes place in or near the home is growing all over the world. An unknown number of children in developing and industrialized countries alike — above all, girls — are at risk of sexual abuse by relatives, other members of the child’s community, or strangers. Sexual abuse in the home is also a significant factor in pushing children to leave home, thereby perpetuating a cycle of vulnerability.

A study in Zimbabwe found that most cases of child sexual abuse probably go unreported. Some are detected when the child develops a sexually transmitted disease — proof that abuse took the form of actual sexual intercourse. For example, during a one-year period 907 children under 12 were treated for a sexually transmitted disease at the Genito-Urinary Centre in Harare. Most of the offenders responsible for passing these infections to the child were either neighbours or close relatives.

While in some cases sex takes the form of actual rape, in many instances it ranges from enticement to coercion. The growing phenomenon of “sugar daddies” illustrates the grey area surrounding the exchange of sex for goods and cash. These are older men who seek out young girls (often because they believe they are at less HIV risk from children) and entice them into sex with offers of meals, clothes, luxuries and cash, including money for school fees. The age disparity between the girls and their sugar daddies, who are older and sexually experienced men, creates a particularly great HIV risk for the children.

Girls employed as domestics are vulnerable to another type of sexual abuser — the male head of household, or his sons. Occupational exposure to sexual coercion is, of course, not restricted to household employees, but live-in domestics run a particularly great risk because they are accessible around the clock.

Sanctions and laws are only a first step in stopping child sexual abuse. In the shorter term they may raise awareness of this terrible affliction. Increased attention will in turn help change the culture of silence surrounding abuse and make societies more sensitive to abused and exploited children. But while laws forbidding sexual exploitation of children exist in nearly every nation on earth, they are notoriously hard to enforce. Even when cases are brought to court, abused children often make reluctant witnesses.

HIV and consensual sex with peers

Children are at risk of HIV infection not only when they are sexually exploited or abused, but also when they engage in consenting sex. In many countries, many children have their first sexual relationships when they are under the age of 18. Adolescents also engage in unprotected sex with sex workers.

A major source of vulnerability as far as children is concerned is their lack of knowledge about pregnancy and about STD/HIV transmission, and their lack of skills in recognizing situations that may turn risky, such as alcohol consumption, standing up to pressure for sex (and drugs), and negotiating condom use and other forms of safer sex.
Love and trust also make children vulnerable. The rate of partner turnover is often greater during adolescence and the early twenties than in later years. This applies not only to casual partners but to regular relationships which occur one after the other. Although these relationships may not last long, in the minds of young people they are often considered to be “safe” in terms of HIV transmission because they are regular and monogamous. Thus unprotected sex (intercourse without a condom) occurs with a series of partners, but the risk is masked by the apparent monogamy and trust involved in each such relationship. Yet the unwanted pregnancies and high rates of STD infection among young people show that the unintended consequences can be severe and — in a world with AIDS — lethal.

HIV and drug use

In a world with AIDS, the injection of illicit drugs, always a risky behaviour, carries an additional danger — HIV infection. When people of whatever age share needles and syringes to inject drugs, microtransfusions of blood occur — and these are relatively efficient for transmitting HIV and other microbes. Drug injecting is thus a phenomenon that policy-makers, educators and HIV prevention workers concerned with child protection cannot afford to neglect.

Drugs do not have to be injected to carry an HIV risk. Alcohol, smoking drugs or glue-sniffing are apt to make people forgetful or careless about safe sex, and reduce the likelihood of condom use. While some adolescents inject drugs, many more engage in non-injecting use of substances that can increase their vulnerability to HIV infection.

Many factors, both individual and social, influence drug use. However, the association between drug use and HIV infection appears to be particularly dangerous for young people of low socioeconomic status, including girls involved in commercial sex and girls and boys living on the street. The environmental factors involved include poverty, discrimination and lack of access to education and health services. “When surveyed, young people in developed or developing countries often indicate that boredom, curiosity and wanting to feel good are perceived as the main reasons for use. Other functions served by substance abuse are to relieve hunger, to adopt a rebellious stance, to acquire courage to beg or be involved in commercial sex, to keep awake or get to sleep, and to dream”, says a WHO report.

Children in difficult circumstances are more apt to maintain and escalate substance abuse. For girls living or working on the street, the risks are particularly great, since they often have to cope with violence, HIV and other STDs, unplanned pregnancies and unsafe abortions. If they carry their pregnancies to term, they are often left to their own devices to support themselves and provide for their children.

Refugee and displaced children

As civil conflict, political persecution, and natural disasters continue to plague many countries, millions of people are forced to live outside their countries of origin. The majority of the world’s refugees are children and women. In conditions ranging from large rural encampments with very limited infrastructure to intensely crowded urban shanty towns, young refugees are particularly vulnerable to nonconsensual sex. Even if there is consent the availability of condoms is often quite limited.

The same is also true for many displaced children who remain within the borders of their country, but not in their homes. They survive in very unstable, often threatening environments where risks are high and rights are rarely protected. To make matters worse, refugee and displaced children are known to be targeted for rape and sexual abuse by adult tormentors from within their own communities, and from external exploiters taking advantage of these environments in which children’s rights are often violated.

Children in detention and HIV

Similar to the saga of their adult counterparts in prisons, children who are in detention or remand centres are often exposed to violence, abuse, and unwanted sex. Drug abuse is also a compounding factor for HIV transmission, along with the prohibition of condoms; so are body piercing and unsanitary/unsafe tattooing. Young people in reformatories and other such facilities often have few, if any, options for preventing HIV and other sexually transmitted diseases. Without radical reform in juvenile justice and social welfare institutions, these children will remain with their rights violated — and their risks increased.
**Strengthening development to strengthen coping**

The socioeconomic costs of AIDS are affecting the ability of developing economies to sustain their development gains — and this has enormous repercussions on children.

Other diseases have profound effects on the survival and well-being of children. But a distinctive feature of AIDS is that it affects a tremendous number of young people who are also parents — adults in their most sexually active and most productive years. In the worst-hit areas, resources become increasingly stretched as AIDS mortality increases the burden of income-generation and child care and places it on the shoulders of fewer and less able-bodied adults. AIDS stigma can affect the willingness of communities and extended families to care for and support those who are most affected. Society’s coping capacity is further adversely affected by the fact that the effects of HIV manifest themselves over periods of years and that AIDS deaths tend to be clustered within families, with very often more than one parent and more than one child in a particular household becoming infected.

However, it is still difficult to make reliable estimates of the impact of AIDS on economies, because AIDS impacts differently on different socioeconomic systems and even on different sectors within the same economy. For example, the loss of a single income earner in a family may have a different impact in rural and urban areas according to the type of family structures. In urban areas, the loss of a single wage earner can affect a large group of extended family members. Labour-intensive farming systems are also more vulnerable to the loss of able-bodied adults than others.

Improving understanding of these issues is not just of theoretical interest. It is a practical necessity. Unless knowledge of the socioeconomic effects of AIDS improves and is reflected in planning and policy development, strained economies around the world will tend to consider HIV/AIDS as just one more competing need to respond to, and may find it increasingly difficult to allocate resources for prevention programmes.

Just as importantly, a deeper understanding of these issues strengthens the argument for building up development as a way of helping families and communities withstand the impact of AIDS.

A shift of emphasis is needed away from relief towards longer-term intersectoral approaches to meeting the needs of AIDS-affected children. A relief approach of providing directly for children’s needs is generally not sustainable where the number of affected children is large. Wherever possible, resources should be directed to enabling families and communities to establish and maintain a sufficient economic base to provide for children’s needs. Children themselves need to have their educational and employment opportunities bolstered if they are to break out of the pernicious cycle of poverty and AIDS.

While children are an increasing part of the AIDS problem, they are also a critical part of the solution. “We have a window of hope between the ages of 5 and 18 years”, says Dr Sam Okware, Uganda’s Commissioner for Health. “If that group can be educated, if their behaviour change can be modulated to ensure they do not have risk behaviour, I think we have a future.”

Education and empowerment combined with the promotion of children’s rights are believed by leading agencies such as UNICEF and UNESCO to be key to HIV/AIDS prevention. However, much of this needs to be directed not only to the youngsters themselves but to their families — the most important social support for children. Reducing children’s vulnerability to HIV means improving the economic situation of their families. Development agencies such as UNDP have repeatedly emphasized the need to create micro-funds, micro-credit schemes, rural employment schemes and other instruments that can raise living standards and ensure sustainable livelihoods for children and their families. Reducing children’s vulnerability also means keeping the various communities’ HIV risks constantly in mind when, for example, targeting development assistance. In northern Thailand, for example, the Daughters of Education project
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provides funding for girls who might otherwise be sold into the sex trade to remain in school and develop better employment prospects.

In other words, development not only strengthens society’s ability to cope with the impact of HIV/AIDS. Development strengthens society’s ability to withstand HIV transmission.

School education on HIV/AIDS

Provision of AIDS education and education concerning sexual health is an issue fraught with controversy the world over. The objection to providing education on sexual health is most commonly stated as a fear that such education will encourage early sex. UNAIDS recently commissioned an update of an earlier WHO review of studies — mostly in the USA and Europe — on the effect of sexual health education. The aim was to assess the impact of sexual health education on the behaviour of students in terms of rates of teenage pregnancy, abortion, birth, sexually transmitted diseases, and self-reported sexual activity.

The review showed that responsible and safe behaviour can be learned. Education on sexuality and/or HIV does not encourage increased sexual activity. Quality programmes in fact help delay first intercourse, and protect sexually active young people from sexually transmitted disease, including HIV, and from pregnancy. Among other things, quality programmes feature a clear explanation of the risks of unprotected sex and methods — including abstinence — for avoiding them, and help young people practise communication and negotiation skills. Experience with successful programmes shows that peer-led education has greater credibility and acceptance. The involvement of children themselves in developing messages and approaches is a critical element.

There are questions as to how early the provision of AIDS and sexual health education should begin. Issues such as the increasing evidence of sexual abuse in particular have persuaded some teachers and AIDS workers that some form of “life-skills” education is necessary in primary school. The UNAIDS-commissioned review also found that sexual health education is best started before the onset of sexual activity. Such early education is believed to be particularly important by AIDS workers in developing countries, where secondary school enrollment is much lower than primary, especially for girls. In many countries, the majority of children have left school by the age of 15. Many of these children are poor, are unable to read and write and are among the most vulnerable to HIV infection. Reaching them quickly enough is arguably the highest AIDS prevention priority.

According to one AIDS worker in Zimbabwe, “we start in schools from about 8 years or 9 years old. It sounds too early but in our country there is a lot of child sex abuse, even rape, which makes it very important for us to introduce the subject during that period or even earlier. We want to have this child know that this is my body, nobody has a right to my body, if anybody fidgets around with my body I should report it to my mum and dad so that I am protected. We start talking about the information that helps this child to know who they are and how they can best protect themselves.”

In recognizing the important role children can play in protecting themselves and their communities from HIV, it is equally important to recognize the power that many people and institutional structures may exercise in preventing children from accessing education, information and life-skills training. These “gatekeepers” may be parents, teachers, educators, community and religious leaders, media professionals, policy makers, and government officials. Experience shows, however, that when parents are given the facts, they generally agree on the need for AIDS education. There is an urgent need to bring these gatekeepers on board and gain their cooperation in promoting early life-skills education and prevention for children. This implies the need to provide AIDS and sexual health education also to adults.

Reaching children outside the school setting

Although some of the most intense arguments around AIDS education have centred on sexual health education in the school setting, organizations such as UNICEF and WHO argue that education also needs to be targeted as a high priority for those children who are not in school.

In some countries, up to 80% of children do not continue beyond primary level. It is these groups who are often at higher risk of HIV infection than those who stay in school. Among these children are those living in rural...
areas, in urban slums, those employed in factories, refugees, migrants and those who are sexually exploited.

Street children are among those at greatest risk. Many millions of children and adolescents in the world are working or living on the street, often in violent and dangerous situations. In Brazil alone, there are an estimated 7 million children and adolescents from very poor families living and working on the streets. These groups are some of the most vulnerable to HIV infection and to other dangers. For many, sex may be a means of securing money, food, shelter, protection, comfort or affection.

**Injecting drug use and HIV prevention**

As with the prevention of sexual transmission, HIV prevention related to drug use must encompass far more than the simple provision of information. There must be an emphasis on the acquisition of skills for negotiation, building self-confidence, making the right decisions, resisting peer pressure, and gaining access to prevention tools and drug treatment. The disempowering context within which these children live must be recognized and remedied — for example, the interface between drug use — where stigma is particularly strong vis-à-vis females — and the commercial sexual exploitation of girls.

A key need is to integrate sexual health education and drug prevention education, not conduct them separately, because they are both inextricably intertwined in HIV transmission.

Measures must be designed and carried out in a way that helps build a supportive environment for these children.

Information per se is not enough. HIV prevention means tackling vulnerability at its roots. It means helping the children acquire the skills they need to negotiate safer sex, resist peer pressure for sex and drug use, and establish personal support networks. It also means providing literacy education, training in employment skills, and welfare assistance as necessary. Counselling is important because it helps children mature and make sound decisions. In short, preventing the HIV risk associated with drug use calls for programmes targeted at the drug users themselves, their sex partners and family members, health care workers and the general community. It also requires advocacy to raise the consciousness of adults not to lure children into drug use.

**Involving children**

If children really do offer a “window of hope” for influencing the future course of the AIDS epidemic, understanding their needs and perceptions will be critical.

At an international conference on AIDS in Marrakech in 1995, a “delegation” of young Africans from 11 countries, some as young as 14, issued a declaration of their needs and priorities. “We strongly believe that our energy, idealism and commitment can be used to stop the further spread of the AIDS epidemic that is devastating the social and economic fabric of our countries”, they declared.

At the same time, it must be recognized that children are not alone in this world. Parents, school teachers, religious and community leaders must also be involved in developing programmes for children if these programmes are to be accepted by the community and help build a safe and supportive environment. Securing adults’ involvement requires ensuring that they hear the concerns and aspirations of children. Creative ways can be found of “amplifying” the voice of children. In Thailand, for example, a Children’s Forum has been created in parliament, while a “media page” in newspapers and magazines captures children’s voice and channels their experience to the adult world.

Children and children’s organizations must be recognized for their potential to contribute to families, communities and society. To expand the response to AIDS in countries calls for expanding partnerships with groups representing children — and with children themselves.

**AIDS is the most publicized disease in the world, but its impact on children has received an inadequate response. Adults can and must do their part to ease the suffering of children infected with HIV, help children in AIDS-affected homes and communities, and enable all children living in the shadow of HIV risk to grow up uninfected. But it may be that the epidemic’s future course will be shaped by the actions of those it is increasingly affecting: the children who live in a world with AIDS.**