

# **The Impact of HIV and AIDS on Children: Lights and Shadows in the ‘Successful Case’ of Uganda**

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## **Introduction**

HIV and AIDS, war and civil strife have taken an enormous toll on Ugandan society in the past two decades, causing the deaths of tens of thousands of people and decimating the young and middle-aged portion of the population. The Uganda AIDS Commission (UAC) estimated in 2001 that at least 800,000 people had died of HIV-related illnesses in Uganda since the onset of the disease. The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that a further 94,000 died in 2001 alone. At least 1.7 million children have been orphaned as a result, and the numbers keep rising: UNAIDS reported in 2004 that an estimated 30,000 additional children were orphaned between 2001 and 2003 (UAC 2001; UNAIDS 2004). Children are also affected indirectly and the epidemic has had a major impact on their welfare. Thus, the infant mortality rate (IMR), which had decreased to 97 deaths of children under one per 1,000 live births in 1988–1992, rose to 101 per 1,000 live births in 2000, while life expectancy declined from 48 to 42 years during the same period.

Table 1 shows the numbers of children and adults affected by the epidemic. While the number of people infected with HIV decreased over the two years, the number of people who died increased, as they succumbed to the virus caught 7 to 10 years before. AIDS is the leading cause of mortality in Uganda and is responsible for about 12 per cent of all deaths in the country.

**Table 1. Estimates of AIDS epidemic in Uganda, 1999 and 2000**

Situation	Cases	Year	
		1999	2000
People living with HIV	Total	1,438,000	1,107,644
	Adults	1,294,200	996,880
	Women	761,300	543,753
	Men	532,900	453,127
	Children <15 years	143,800	110,880
New AIDS cases	Total	112,000	99,081
	Adults	100,800	89,173
	Women	54,982	48,640
	Men	45,818	40,533
	Children <15 years	11,200	9,908
Cumulative AIDS deaths since the beginning of the epidemic	Total	838,000	848,492
	Adults	754,200	763,600
	Women	411,382	416,510
	Men	342,818	347,090
	Children <15 years	83,800	84,892

Source: STD/ACPMOH Surveillance Report June 2001.

According to the AIDS Control Programme (ACP) of the Uganda Ministry of Health (MoH), by September 2001, an estimated cumulative total of 2,276,000 people had been infected with HIV since the epidemic was first reported in the country in 1982.

There were almost no attempts to control the epidemic by the government or other agencies until 1986. But from that year onwards, a number of interventions were put in place by the government, non-governmental organizations (NGOs), community-based organizations (CBOs), people living with HIV networks and development partners. By 1997, over 1,200 agencies were engaged in HIV-related activities throughout the country. These efforts had a considerable effect, so that prevalence declined from about 24 per cent in 1992 to 4.1 per cent in 2003 (UNAIDS 2004).

Despite the progress, HIV has significantly affected the labour market, particularly as over 80 per cent of cases occur in the 15- to 45-year age group. The continued attrition rate of deaths in young adults has had a social and economic impact, particularly on children, that has increased with the severity and duration of the epidemic. Without adequate care and support, children's health, nutrition and education suffer and many are subjected to rejection, discrimination, fear, loneliness and depression.

## The evolution of the AIDS epidemic

The AIDS epidemic in Uganda has evolved through four distinct phases since it first emerged in 1982.

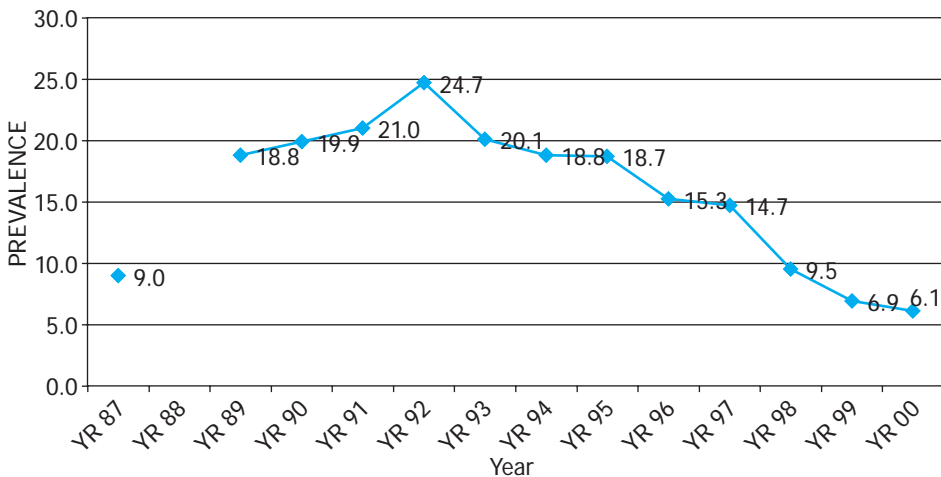
**Phase 1, 1982–1986:** The first two cases of AIDS were identified as ‘slim disease’ in 1982 in the southern district of Rakai on the shores of Lake Victoria. The following year, 17 more cases of ‘slim disease’ were reported and then in 1984 the ‘slim disease’ was confirmed as AIDS. The cases were limited to high-risk groups such as sex workers, truck drivers, the military and youth with multiple partners, and they were mainly confined to large urban areas.

**Phase 2, 1987–1991:** From 1987 to 1998, the disease spread to the business community and smaller urban areas. By 1990, AIDS cases had been reported in almost all districts of the country, with urban centres along the major roads the most affected. There were particularly increased infection rates in the northern part of the country in the early 1990s, due to armed conflict and the resulting breakdown in the social infrastructure.

**Phase 3, 1991–1993:** The epidemic peaked in 1992 and spread to rural areas, with all districts affected. The prevalence reached 30 per cent in some hard-hit areas, such as Mbarara Town in Western Uganda.

**Phase 4, 1993 to date:** From 1992 to 1998 there was a relatively sharp decline in trends, followed by a slowdown in the decline as indicated in figure 1.

Figure 1. HIV-1 prevalence in Uganda (1987–2000)



Sources: STI/ACP Surveillance Report 2001 and other previous MoH Uganda reports.

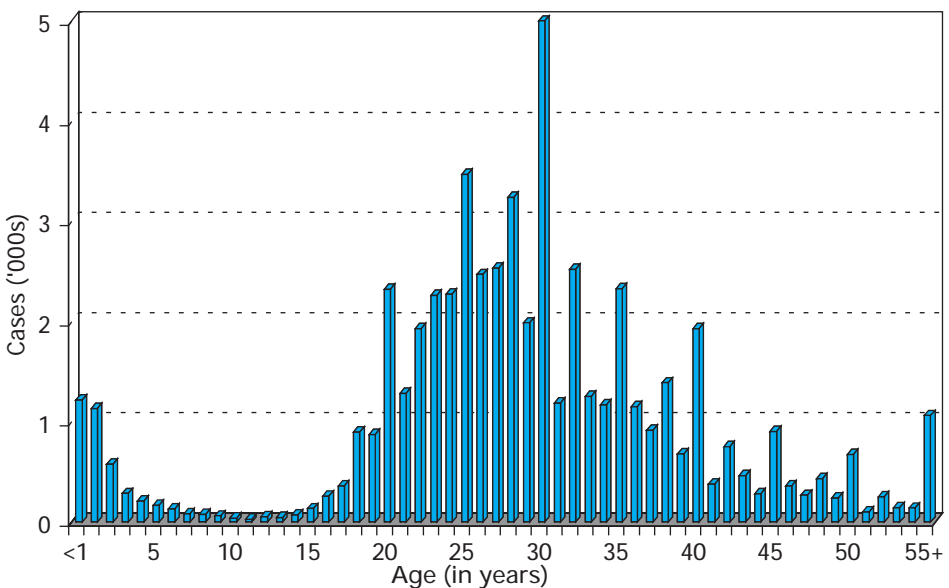
## Social epidemiology of HIV

### Variations in HIV prevalence

**Regional variations:** The establishment of sentinel surveillance sites for HIV information centres has made it possible to keep track of trends. According to these data, prevalence in Uganda has varied from 5 per cent at the sites in most rural districts, such as Moyo, to as high as 30 per cent at some urban ones, such as Mbarara (Kayita and Kyakulaga 1997). Kampala, Masaka, Jinja and Rakai are said to have more than 500 AIDS cases per 100,000 residents. The large number of cases in Kampala and Jinja is attributed to the high concentration of urban residents, whereas in Masaka and Rakai, although they are rural, it is mainly due to the fact that AIDS was first identified there. Districts such as Gulu, Kitgum, Luwero, Kiboga, Kabarole, Kasese and Mpigi, all of which have been affected by war, have between 200 and 500 cases per 100,000 residents.

**Differentials according to age and sex:** As shown in figures 2 and 3, the HIV infection rate varies significantly by age and sex. Prevalence is very low for children 14 and under, but begins to rise in the age group 15–19, particularly among girls. Mother-to-child transmission (MTCT) of HIV is responsible for the infection rate among children. About 15 per cent of the children breastfed by infected mothers acquire the virus (WHO, UNICEF, UNAIDS 1999). The impact of HIV on women has been considerable. In 1987, a national sero-survey revealed that the

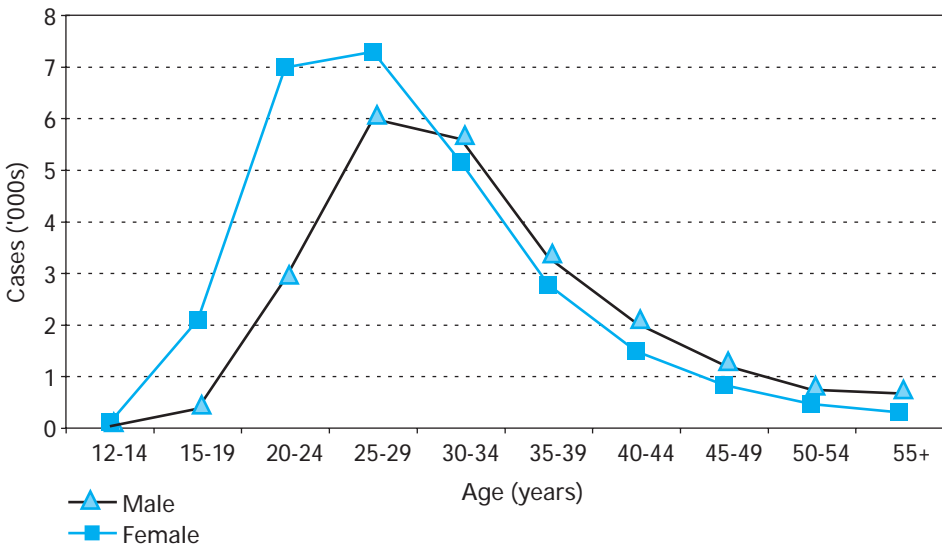
Figure 2. Age of Ugandan AIDS cases



ratio of men to women infected was close to 1:1, but a decade later, a study showed that females under 25 were twice or three times more likely to be HIV-positive than men (Kayita and Kyakulaga 1997). Other studies show similar trends. Data indicate that the difference in prevalence between the sexes is particularly marked in the 15–19 year age group, when girls are three to six times more likely to be infected than boys. The gap reduces somewhat between the ages of 24 to 29, but after the age of 30, on average males have a higher prevalence than females.

Figure 2 indicates the vulnerability of newborns who are infected by their mothers. Most of these babies only live for a year or so and few survive beyond the age of five.

**Figure 3. Distribution of adult AIDS cases by age and sex**



## Surveillance systems

Seroprevalence rates in Uganda are derived from three sources. First, there are population-based cohort studies in several districts. Second, there is the AIDS information centre (AIC), which compiles data from voluntary counselling and testing (VCT) in various parts of the country. Data from AIC have helped to identify the vulnerable groups, predict the future direction of the epidemic and prioritize interventions and target groups. Third, there are the 15 antenatal sentinel sites. Although they only provide data on women, the 250–600 blood samples collected quarterly give a realistic picture of the geographical patterns of HIV prevalence and its relationship to STI rates.

**Figure 4. HIV infection rates among antenatal clinic attendees at selected sites in Uganda**

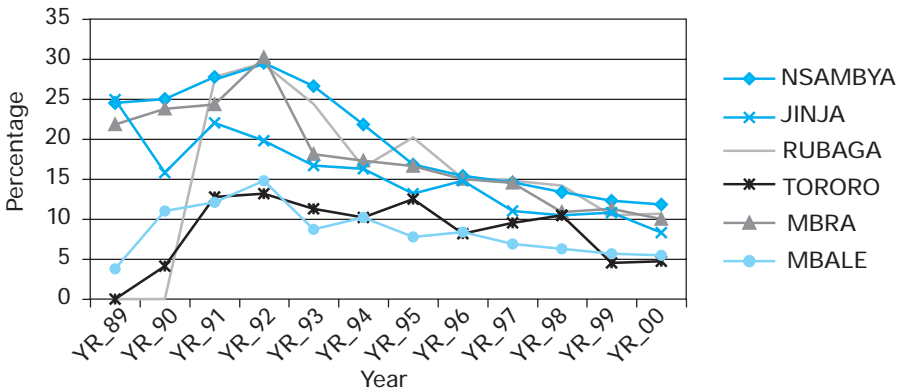


Figure 4 highlights how the epidemic has evolved, peaking in 1992 and then gradually declining.

*AIDS case surveillance*

Surveillance data on diagnosed cases of AIDS (based on the WHO clinical AIDS case definition) is collected from health units. However, some health units are more active at reporting than others. Therefore, the number of cases reported does not necessarily reflect the magnitude of the situation.

*Paediatric AIDS case reports*

Management and reporting of paediatric AIDS cases remains a big challenge, and the reported cumulative total of 58,165 in 2000 was estimated to be less than 25 per cent of the actual cases. This is due to poor case surveillance by the health care system, especially in the rural units, before 1996. Paediatric AIDS cases are on the increase because of the number of HIV-positive women of reproductive age. As of the end of 2003, UNAIDS estimated that 80,000 children were living with HIV (UNAIDS 2004).

**Table 2. Paediatric AIDS cases, 1996–2000**

Year	Number of cases
Prior to Jan 1996	3,754
1996	35
1997	85
1998	81
1999	111
2000	220
Total paediatric cases	58,165

### *HIV and opportunistic infections*

HIV infection has led to the resurgence of other diseases such as tuberculosis (TB), pneumonia and meningitis. By September 2001, there were 35,497 cases of TB reported to the National Tuberculosis and Leprosy Programme. A study conducted among a paediatric cohort revealed that 18 per cent of the HIV-infected infants developed TB compared to 1.4 per cent of the non-HIV-infected, and that only a third of the HIV-infected children responded to TB treatment. The country has adopted the strategy of directly observed therapy (DOT), which is largely community-based, not so much because it is cost effective as because there are insufficient in-patient facilities to cope with the increasing number of cases of TB.

### *Main routes of transmission*

According to the Ministry of Health (MoH) 1997 surveillance report on sexually transmitted infections (STIs) and HIV (MoH 1997), the main routes of HIV transmission in Uganda include:

1. Heterosexual contact with an infected partner (75–80 per cent).
2. Mother-to-child transmission of HIV through birth or breastfeeding (18–22 per cent).
3. Infected blood, blood products and septic conditions in health facilities (less than 2 per cent).
4. Use of non-sterile sharp piercing instruments (less than 1 per cent).

**Mother-to-child transmission (MTCT) of HIV:** A collaborative study by Makerere University/Case Western Reserve University found that about 26 per cent of seropositive mothers transmit the virus to their children before, during and after delivery. Over 90 per cent of children with HIV infection are infected by their mothers; less than 10 per cent of them acquire HIV infection from blood products or from contact with non-sterile skin-piercing instruments. WHO, UNAIDS, UNICEF (1999) estimate that a child breastfeeding from a mother who is HIV-positive has a 15–25 per cent risk of infection.

The increasing trend of HIV/MTCT is attributed to the fact that many mothers are HIV-positive long before developing AIDS, so they continue bearing children without knowing that they are infecting them (UAC and UNAIDS 2000). Also some people who know they are HIV-positive get married in order to avoid society's ostracism and ridicule, or dying without a child or heir.

**Circumcision:** Some ethnic groups, such as the Bakonjo and Bamba in Western Uganda and Sabinu and Bagisu in Eastern Uganda (10 per cent of the population), initiate young men into adulthood through ritual circumcision. These traditional operations are generally carried out during adolescence, often after the onset of puberty, and the sterility and safety of the instruments used is a cause for concern.

In addition, the male circumcision ceremonies are often accompanied by sex with multiple partners (Olowo-Freers and Barton 1992). Muslim communities, who constitute about 10 per cent of the country's total population, circumcise males according to the precepts of their religion. The procedure is usually done in hospital under sterile conditions, thus limiting the potential for infection.

According to the United Nations (UNFPA 2000), a few communities in Uganda (2 per cent) practise female genital mutilation/cutting (FGM/C). However, the tradition appears to be declining as girls become educated and aware of the potential for HIV infection (Kiiry 1997).

### **Risk behaviour**

**Sex workers:** Commercial sex is against the law in Uganda, so it is difficult to ascertain the total number of sex workers in the country. Although traditionally sex was restricted to marriage, this is no longer the case. As a result, the age bracket of sex workers has widened and this has implications for HIV, particularly if the sex is unprotected. According to a knowledge, attitude, behaviour and practice (KABP) survey on HIV and STIs among 166 sex workers (SWs) in Kampala, Uganda (1998), the majority of the SWs (72.9 per cent) were young women aged 15–24 years, 31.5 per cent of them still teenagers. About two thirds (60.5 per cent) of the SWs reported having children, nearly half of whom were two years and under. These children are clearly at risk, especially if their mothers are infected.

Close to four fifths (78.7 per cent) of the SWs had a relative, friend or colleague who had AIDS, and 12.3 per cent reported having lost a sexual partner to the disease. Knowledge of prevention against HIV infection was high and 95.5 per cent of SWs reported using a condom during their last intercourse. Over three quarters of those studied (77.1 per cent) were able to cite two or more preventive practices. This shows that there is a high level of awareness about HIV and prevention is being given priority. With proper targeted sex education this can be increased.

**Truckers, fishermen and other related occupations:** Truckers, taxi drivers, fishermen, the armed forces, waitresses, barmaids and market vendors are considered at higher risk than subsistence farmers or government workers, who are referred to as low-risk groups. Kirunga (1997) found that 38.3 per cent of the high-risk groups were HIV-positive, compared to 24.2 per cent of other groups and 17.7 per cent of low-risk groups. About 75 per cent of the deaths of truck drivers are said to be due to AIDS.

**Refugees and internally displaced persons (IDPs):** Refugees and IDPs, who are mainly women, children and the elderly, usually live in temporary rural camps. Although data on HIV prevalence in such groups are not available, they are considered at risk due to the social, economic and psychological breakdown so often



prevalent in the camps. Risk factors include transactional sex to escape to safety, gain access to shelter or other services, and the deliberate use by men of sex as a weapon to demonstrate power and inflict pain and humiliation on women, children and other men (UAC and UNAIDS 2000).

STI studies conducted in northern Uganda, where over 50 per cent of the refugee and IDP population are located, found that there was high STI prevalence linked to army movements, camp following and commercial sex. Early sexual activity among boys and girls and unwanted pregnancies were also high (Barton and Mutiti 1998).

### *Other social risk factors*

**HIV and culture:** Studies show that traditional practices such as widow inheritance, polygamy and wife-sharing are significant factors in HIV transmission (Barton and Wamai 1994). Other cultural traditions such as blood brotherhood and treatments for infertility also create a conducive environment for the spread of HIV.

In many ethnic groups it is the tradition for a widow and her children to be automatically inherited by her dead husband's brother as a means of protection. Deaths are followed by funeral rites that include the consumption of alcohol and sexual activity as an accepted means of giving social support to the bereaved. However, these practices are gradually changing as communities realize that they may increase the risk of HIV infection. Large areas of the country have begun supporting widows and their children without direct inheritance (Olowo-Freers and Barton 1992).

Other cultural factors that perpetuate HIV infection include the reluctance of parents and other adults to talk to young people about sex, and stereotypical male/female roles, which encourage submissiveness for girls and aggressiveness for boys.

**Linkages between alcohol and HIV:** Women sell alcohol as a means of generating income for their families, but the activity is also associated with risky sexual behaviour. According to a Uganda Police Headquarters report, alcohol consumption at social occasions such as weddings, funerals, circumcision rituals and graduation parties increases the potential for extracurricular sexual activity and even rape, which can raise levels of HIV infection. At the start of interventions against the epidemic in the 1980s, community leaders were very keen on restricting the opening hours of discothèques and other places of amusement for youth where alcohol is consumed in large amounts. However, with time, this has been dropped and there is now reliance on the use of condoms and public education and information on control and prevention of HIV.

## **The impact of HIV on the well-being of children**

The impact of HIV on the health, education and social well-being of children in Uganda has been profound.

### **Impact on children's health**

In contrast to trends in the industrialized world, life expectancy in Uganda decreased from 48 years in 1985 to 42 years in 2000 and is projected to decline further, although at a reduced rate. At the same time, projections for the infant mortality rate (IMR) show an upward trend due to AIDS (table 3).

**Table 3. Selected indicators of child well-being (health)**

Year	1985	1990	1995	2000
Life expectancy at birth (years)	48	43	41	42
Infant mortality rate (per 1,000 live births)	88	89	90.5	88.4
Infant mortality due to AIDS (per 1,000 live births)	10	11	12	–
Under 5 mortality rate (per 1,000 live births)	164	163.2	162.9	152
Infants with low birth weight (< 2.5 kilos)	–	10%	12%	12%
Children under 5 suffering from moderate to severe wasting	5%	26%	23%	13%
DPT3 immunization coverage	31%	67%	61%	46.6%
Measles immunization coverage	–	60%	59%	56.6%
ORT use	–	–	46%	43%
Women attended by professional during pregnancy	–	91%	91%	89.2%
Proportion of births attended by skilled personnel (midwife, nurse, doctor etc.)	–	38%	38%	25.2%

Source: Various reports.

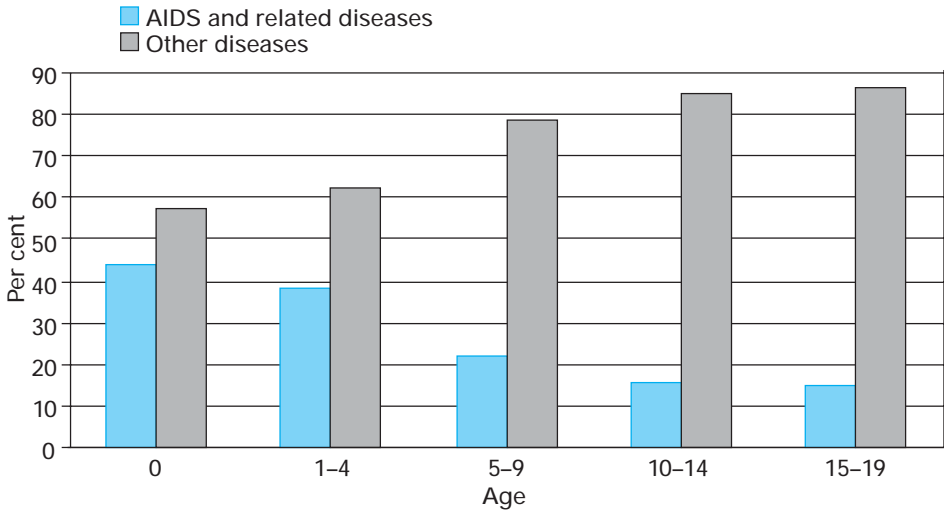
AIDS affects not only childhood mortality but also the pattern of illness and disease observed in children, as indicated in figure 5.

Ntozi (1997) conducted a study in six districts of Uganda on AIDS and its impact. In this study, a sample of households that had experienced death in the last 10 years was selected and household heads or competent persons interviewed. For each household member who was ill or had been sick in the last four weeks before the survey, questions were asked regarding the name, sex, age, type of illness and duration of sickness. As shown in figure 5, AIDS and related diseases featured as a cause of illness for the under-fives much more than for older children.

Presumably this was because most of the HIV-positive children had died by the age of five.

Although this study relied on respondents' perceptions, it provides a picture of the pattern of morbidity.

**Figure 5. Reported illness by cause for children in six districts in Uganda**



Source: Ntozi 1997.

**Nutrition:** Results from the baseline findings in a June 2001 study on children affected by HIV reveal that nearly a fifth (19.6 per cent) of older children and 15.2 per cent of younger children reported not getting enough food to eat a few times a week or more. Interestingly, older orphans are the most likely (24.8 per cent) to report not getting enough to eat a few times a week or more (Gilborn et al. 2001).

### Impact on the health sector

In Uganda, as in the rest of sub-Saharan Africa, AIDS is the leading cause of mortality, ahead of malaria, tuberculosis and other diseases (chapter 11). According to the MoH Management Information System, AIDS is responsible for up to 12 per cent of deaths in Uganda, is a leading killer of adults aged 15–49 years, and the fourth leading cause of death among under-five children. Only about 1.2 per cent of the health budget is specifically dedicated to HIV, though a considerable part of the general health infrastructure is used for care of HIV-infected patients. As in Botswana, the Democratic Republic of the Congo, Rwanda, South Africa and Zambia, about half the available hospital beds are occupied by those with AIDS and related opportunistic infections.

Only 49 per cent of Ugandans reside within 5km of a health facility, and only two fifths (40 per cent) of the units have achieved a minimum staffing norm. The ratio of doctors to people in Uganda is 1:18,000, while that of nurses is 1:3,000. The problems of staffing and access to health services are being addressed through the creation of health subdistricts. On 1 March 2001, cost-sharing in public facilities was abolished because it was found that 43 per cent of the people in rural areas and 36 per cent in urban areas could not seek health care due to lack of money. In some districts, up to 71 per cent could not afford to access health care (Ministry of Finance, Planning and Economic Development 2001).

Data are not very clear on the extent to which health sector personnel are affected by AIDS, but a 2001 study in Arua hospital showed that 72 per cent of the 36 deaths of staff recorded were due to AIDS (Amandua 2001).

**Table 4. Causes of mortality among workers in Arua hospital**

Disease	Number	Percentage
AIDS	26	72
Alcohol	6	17
Other	4	11
Total	36	100

Source: Amandua 2001.

However, whereas HIV has had severe negative consequences on individuals and the economy, some interventions have had a positive impact on service delivery outside the scope of HIV. The number of health educators increased from 7 to 347 over a decade and 12 health education films were bought. This was an innovative strategy to combat the epidemic, and health education sessions address not only HIV but also other top killer diseases such as diarrhoea and malaria. Facilities with PMTCT of HIV have improved obstetric services by introducing better practices, such as counselling, laboratory check-ups and postnatal care. Screening of blood is done for other endemic diseases transmitted through blood transfusions such as syphilis and hepatitis B. Infection control has been addressed, especially the use of gloves in obstetric care and sterilization of equipment. Before the advent of HIV, these measures were not in place, so it may be argued that the HIV epidemic has led to some significant improvements in general health service delivery in Uganda.

### **Impact on education**

The impact of HIV on the education of children can be viewed from two different perspectives, the first being the school performance of the children themselves,

and the second the impact in terms of staffing and the quality of education. Data on the number of orphans or children of patients with HIV-related illness dropping out of school are not readily available, but by combining information from the Ministry of Education and Sports with surveys on children orphaned by AIDS, it was possible to get an indication of the impact of HIV on school dropout. Table 5 shows the total enrolment and drop-out rate for primary school. The percentage of children dropping out due to HIV increased from 45 per cent in 1995 to 53 per cent in 1999. Another survey (Ntozi 1997) revealed that 54.6 per cent of orphans had lost their parents due to AIDS and that 58 per cent of all orphans had problems with money. Although children are entitled to free primary education due to universal primary education (UPE), they have to pay for school materials. Therefore a large proportion of children, particularly those caring for sick relatives or orphaned by AIDS, still cannot afford to attend. Even those who do manage to remain in school face problems of lack of parental guidance, inadequate socialization, and insufficient financial and material support.

**Table 5. Impact of HIV on schoolchildren in Uganda**

Year	All Primary Schoolchildren			All Orphans		
	Enrolment	Dropouts	% dropout	Enrolment	% dropout	% dropout due to AIDS
1995	4,357	2,794	64%	593	77%	45%
1996	5,020	3,492	70%	789	83%	48%
1997	6,403	4,871	76%	892	91%	53%
1998	6,403	4,822	75%	797	90%	52%
1999	6,414	4,879	76%	870	91%	53%

Source: Hyde et al. 2002.

After dropping out of school, the consequent lack of skills and qualifications further exacerbates the children's poverty.

HIV, of course, affects the teacher and pupil population. Absenteeism from work by professional and support staff is mainly due to intermittent sickness, fear, stigmatization, worries, distress and apathy. There are no reliable estimates of the extent of teacher absenteeism due to HIV, but attrition from service due to death is better documented (table 6). The rate is higher in secondary than in primary schools (average 3 per cent for primary and 4 per cent for secondary) over a four-year period. The HIV epidemic caused the death of 450 teachers in the year 2000, as compared to 53 in 1995, an increase of over 8.5 times.

**Table 6. Attrition and mortality among primary and secondary schoolteachers<sup>1</sup>**

	PRIMARY			SECONDARY				
	1995	1996	1997	1998	1995	1996	1997	1998
Total deaths	646	792	987	948	166	158	137	160
Total in post	74,401	81,564	88,751	100,946	12,918	13,997	13,470	16,206
Attrition rate	6.5	5.3	4.3	5.3	4.2	3.6	3.2	4.1
Total mortality rate	0.87%	0.97%	1.11%	0.94%	1.28%	1.13%	1.02%	0.99%
Total mortality as percentage of all attrition <sup>2</sup>	13	17.9	25.45	17.66	30	31.2	31.9	23.95
AIDS deaths as a result of total attrition	2.65	3.82	5.34	3.71	3.71	6.54	1.34	5.03
Estimated AIDS deaths among teachers (21% of total mortality) <sup>3</sup>	136	166	207	199	35	33	29	34
AIDS deaths at 2003 rate for general population	320	320	382	434	56	60	53	70

Source: Hyde et al. 2002.

**Quality of education:** The impact of HIV on the quality of education is demonstrated by the lowered productivity and reduced efficiency of staff due to intermittent sickness, absenteeism and depression. It is also estimated by UNAIDS and UNICEF that in 2000, out of 5 million primary school students, 81,000 lost a teacher due to AIDS. This has increased the workload of the remaining teachers, in addition to their extra responsibilities resulting from the push towards UPE. Over 90 per cent of children are in government-aided primary schools. The government meets the statutory primary school fees for a maximum of four children per family and also undertakes to provide building materials not locally available such as iron sheets, timber, cement and nails, in addition to instructional materials and payment of teachers' wages.

Following the rapid growth of enrolment at primary level, the government intends to increase the quantity and quality of secondary education. Privately owned schools are encouraged in order to meet the growing demand. The number of secondary schools has sharply increased since UPE was declared in 1996, but transition rates between primary and secondary are still relatively low and fell between 1995 and 1997 (from 41.6 per cent to 35.8 per cent), with the availability of secondary school places being the limiting factor. It is particularly important for children orphaned by AIDS to have access to secondary education or technical training in order to equip them with useful practical skills for income generation.

## Impact on the social welfare of children

The impact of HIV on the welfare of children has a number of dimensions, ranging from orphanhood, depletion of family assets, family breakdown, child abuse, drugs and lack of proper homes. Frequently children land up living on the streets.

**Children orphaned by AIDS:** Estimates of the numbers of children orphaned by AIDS in Uganda vary widely: while UAC estimated 1.7 million in 2000, Hunter and Williamson (2000) put the number as high as 2.35 million at the start of the millennium. There are no exact figures, but all agree that there is a very severe problem, because losing a parent for any cause is traumatic, and parental death from AIDS has a particularly powerful effect on a child. Table 7 summarizes some of the socioeconomic impacts at different levels (USAID 2002).

**Table 7. Socioeconomic impact of HIV and AIDS on orphans**

Level	Potential Socioeconomic Impacts		Mitigating/Aggravating Factors
	Short-term	Long-term	
Orphan	<ul style="list-style-type: none"> <li>• Loss of inheritance</li> <li>• Reduced health, nutrition</li> <li>• Reduced school attendance</li> <li>• Increased labour</li> <li>• Increased social isolation, vulnerability and abuse</li> <li>• Increased homelessness</li> </ul>	<ul style="list-style-type: none"> <li>• Reduced productivity</li> <li>• Reduced socialization</li> </ul>	<ul style="list-style-type: none"> <li>• Cause of death of parent(s)</li> <li>• Family or non-family living arrangement</li> <li>• Head of household</li> <li>• Personal characteristics (age, health, sex)</li> <li>• Family, community factors</li> </ul>
Family	<ul style="list-style-type: none"> <li>• Increased dependency ratio</li> <li>• Increased poverty</li> <li>• Increased workload</li> <li>• Reduced per person food consumption and uptake of services (education, health)</li> </ul>	<ul style="list-style-type: none"> <li>• Entrenched poverty</li> <li>• Further breakdown of traditional extended family structures</li> </ul>	<ul style="list-style-type: none"> <li>• Previous family income and assets</li> <li>• Number, age, health of orphans</li> <li>• Cause of death of parent(s)</li> <li>• Head of household</li> <li>• Availability of aid</li> </ul>
Community and nation	<ul style="list-style-type: none"> <li>• Increased poverty</li> <li>• Reduced child health, school enrolment</li> <li>• Increased inequalities</li> <li>• Increased crime, homelessness</li> <li>• Increased social instability</li> <li>• Changes in cultural practices</li> <li>• Diversion of resources for orphan care</li> </ul>	<ul style="list-style-type: none"> <li>• Reduced quality of human capital</li> <li>• Entrenched poverty</li> <li>• Increased inequalities</li> <li>• Reduced economic growth, development</li> <li>• Increased social, political instability</li> <li>• Diversion of resources for orphan care</li> </ul>	<ul style="list-style-type: none"> <li>• Historical economic strength</li> <li>• Access to services</li> <li>• Availability of assistance programmes</li> <li>• Effective anti-poverty programmes for orphans</li> </ul>

Source: USAID 2002.

USAID (2002) estimated that the implicit annual 'tax' on orphan households from reduced income in 1999/2000 would be equal to \$246, or a quarter of the average household's income for an entire year.

In a 1997 study of the psychological effect of loss of parents in Rakai district (a district with one of the highest rates of HIV), Sengendo and Nambi found that, of children orphaned by AIDS, 7.3 per cent lived with their fathers, 20.2 per cent lived with their mothers, 22.8 per cent with their grandparents, and 11.9 per cent with other relatives. The highest percentage of all, 25.3 per cent, lived on their own in child-headed households. Only slightly over a tenth, 12.4 per cent, of children surveyed lived in intact families. This is comparable with another study on the effects of HIV on children (Ntozi 1997), where almost half the orphans were staying with the remaining parent (41 per cent), a quarter lived with grandparents and one fifth with relatives. The majority of the decision-making on the care of orphans was by clan members (30 per cent) and 27 per cent by parents, but 25 per cent was by the affected children themselves. The rest of the decision-making was by grandparents (15 per cent) and friends and other relatives. Evidence showed that half the children (49.2 per cent) were depressed and their situation was affected when their parents became sick, while 27 per cent of the children surveyed were too young to articulate their feelings. About 9 per cent dropped out of school and 5 per cent left school to care for sick parents, but 7 per cent managed to continue their schooling while caring for the sick parents and almost a third (28 per cent) did not have their schooling disrupted.

After the parents' death, only a fifth (19 per cent) continued with undisrupted schooling, 21 per cent lost school time, 12 per cent left school and 29 per cent were too young to tell. This study also revealed that children with one surviving parent had the highest chances of continuing with their education (mother 43 per cent and father 31 per cent). Only 7 per cent of those fostered by grandparents before and after the death of the parents had undisrupted education. The same study also revealed children's reactions at their parents' death as sad and scared (11 per cent), very sad and helpless (50 per cent), cried (11 per cent), sad but determined to face the future (2 per cent), and 25 per cent were too young to tell. There was no response from 4 per cent. The study found that children (10–14 years) living with their widowed fathers were significantly more depressed than older children in the same position, and those living with widowed fathers were more depressed than those living with widowed mothers.

Orphans face a number of problems other than depression. Ntozi's study found that more than half (57.6 per cent) had a serious lack of money, almost a third (31.4 per cent) lacked parental care and only a tenth (7.1 per cent) were unaffected. The extent to which child abuse is linked to HIV is unknown, but a media analysis report on child abuse and neglect revealed that 17.3 per cent were maternal orphans, 16.4 per cent were paternal orphans and 46.2 per cent had lost both parents.



## **Economic impact**

Loss of skilled labour in the public and private sectors is increasingly affecting productivity and increasing expenditure on the labour force. The findings of a 2000 survey by the Ministry of Public Service on the trends and impact of HIV on public services in the country reflected that up to 13 per cent of public officials were HIV-positive and between 15.2 per cent and 27.4 per cent had died of HIV-related illnesses between 1995 and 1999.

The study also showed that the government spent about \$3 million on HIV-related sickness and the deaths of public officials in 1999. This figure constituted 56 per cent of the total expenditure on staff morbidity and mortality (medical and burial expenses, pensions and gratuities) in 1999. The epidemic also caused an increase in indirect costs related to loss of skills and experience, hiring of new personnel, training and loss of staff-hours. As costs increase, production is also affected. There is an estimated annual loss to GDP of 0.9 per cent due to HIV.

Health costs for private companies have also risen. The estimated cost of hospitalization for a patient with HIV-related illness is 300 times that for an employee with other medical problems. Perhaps it is for this reason that HIV has caused employment insecurity and discrimination in the labour force. Some organizations subject prospective employees to mandatory but covert screening tests before recruitment, and HIV-positive people are denied posts. Those who become positive while employed are often discriminated against and their job contracts terminated (UAC and UNAIDS 2000).

Over 80 per cent of the reported AIDS cases occur in people aged 15–45 years (MoH 1997). This age group constitutes the largest part of the potential and most productive labour force, in a way affecting household income. A survey in one district (Rakai) showed that of the 25 per cent of the households who were cultivating less and less land, 35 per cent were doing so because of HIV-related sickness or death. This has threatened the food security of affected families, worsened their nutritional status, and led to a decline in cash-crop production. In households with an average monthly household income of \$18, their AIDS-related expenditure was \$20 for burial and \$40 for the medical costs of a terminally ill patient (Topouzis 1994).

## **Interventions against HIV and AIDS**

### **President's initiative and formulation of AIDS control programmes**

The country's response to HIV and AIDS between 1982 and 1986 was largely confined to the health sector and handled like other epidemics. Most Ugandans thought of the disease as witchcraft, and later as a disease of the immoral, which led to stigmatization of people living with HIV (PLHIV). In 1986, a new government came to power and the new Minister of Health announced the existence

of HIV and AIDS in the country during the World Health Assembly in Geneva. This served as a springboard for nationwide mass awareness campaigns spearheaded by President Museveni. He referred to the menace of AIDS in his speeches as he toured the country, urging his audience to avoid reckless sexual behaviour to minimize the spread of HIV. The First Lady supported this campaign by urging people to assist families affected by HIV. She later founded the organization Uganda Women's Effort to Save Orphans (UWESO), which was originally founded to assist war orphans, but quickly expanded to include those orphaned by AIDS. Consultations on the multi-sectoral approach, spearheaded by the President, resulted in the formulation of the National AIDS Commission in 1992. The President himself chaired initial meetings that led to the formation of UAC. Every politician was required to campaign against HIV at all mass gatherings. This slowly demystified the disease as people gained more insight into their vulnerability to infection and prevention measures.

The government had already established the AIDS Control Programme within the MoH in October 1986. It was the first national HIV control programme in the world. The government then organized an international donors conference in Kampala to gain financial and technical support for HIV prevention and control activities. The 21 international donors who attended the conference pledged immediate support. While the health sector has been the main backbone of the country's response, by 1987 it was recognized that HIV was not only a public health problem, but also a social and economic disaster that called for interventions from all sectors. In August 1990, a national task force on AIDS was appointed to review all HIV control programmes and to suggest a framework for implementation of multisectoral HIV control. In 1992, UAC, which had been set up under the office of the President, was tasked with leading coordination of the multisectoral efforts. HIV control programmes were established in more line ministries by 1994. International agencies, led by the World Bank and including UNDP, UNICEF, and WHO, as well as USAID, supported the development of these structures (UAC 1992).

Realizing that the problem of HIV cannot be solely the responsibility of the government, UAC adopted a holistic approach and worked with the government to strengthen the role of all the relevant actors. The success of the control programme has been achieved with the full involvement of the private sector, business, NGOs, individual families and communities. There is a wide variety of community efforts, targeting economic support to dependants of the sick or deceased in order to sustain income flow and to develop vocational skills for the survivors, especially widows and orphans.

Due to its efforts to reduce HIV prevalence, Uganda has been cited as one of the two success stories in sub-Saharan Africa, the other being Senegal (chapter 3). The key interventions mainly focus on prevention, care and mitigation of the impact of HIV and AIDS.

## Prevention

**IEC to promote behavioural change:** Intensive HIV and AIDS information, education and communication (IEC) campaigns at community level have had a considerable impact on the population. The country established a health education network down to the lowest level of administration, focusing on the districts. The number of health educators (HE) and assistant HEs rose from 7 in 1986 to 347 in 2000. These groups were health personnel already in service who were given additional training and skills in IEC. By 2000, 12 mobile film vans had been purchased to facilitate IEC work. Print and electronic media are also used. There is a weekly page on HIV and AIDS in a local newspaper and daily slots on national radio and television to publicize the danger of HIV and show how it can be avoided.

The IEC programme has led to an increase in knowledge of HIV and AIDS. Data from knowledge, attitude, behaviour and practice (KABP) surveys show almost universal levels of awareness and over 75 per cent levels of knowledge. Two in every three persons are able to cite at least two acceptable ways of protecting against HIV (Uganda Bureau of Statistics 2001). There is also a sustained rise in the age of first sexual activity, increasing use of condoms, especially with non-regular partners, and low reported incidence of urethritis across all the districts surveyed (table 9). It is worth noting that, although there was an increase in non-regular partners (notably for Mbarara and Mpigi), there was a corresponding rise in condom usage. The proportion of sexually active persons who have ever used a condom increased from 71 per cent in 1989 to 72.2 per cent in 2000 in some districts and the nationwide utilization rate was estimated to be 30 per cent (MoH 2001a). Condoms are available in the commercial market and are promoted by the Health Ministry in all health facilities, but they are still inaccessible and unaffordable for the majority of people, particularly in rural areas. The government spends on average \$0.50 per condom provided at service point. The target population for condom distribution is the 15–49 year age group, though Uganda has no clear set target for condom coverage. There are shortages, and at times condoms are out of stock for as much as three months or more.

**Table 8. Comparison of population-based KABP findings for the selected districts of Mbarara, Mpigi, Masindi and Pallisa, various years**

Prevention indicator	Districts Surveyed							
	Mbarara		Mpigi		Masindi		Pallisa	
Year	1997	1999	1996	1999	1997	2000	1997	2000
Knowledge of preventive measures	77.9	78.7	84.8	81.1	74.8	82.2	84.6	76.7
Reported non-regular sexual partners	6.6	8.7	7.3	8.6	6.3	5.2	4.6	4.0
Reported condom use with non-regular partners	31.9	48.0	54.8	71.2	41.5	50.8	30.7	53.3
Reported incidence of urethritis (for men)	12.0	14.2	11.8	8.9	6.7	8.4	13.2	7.6

Source: STI/ACP Surveillance Report 2001.

According to the Uganda Demographic and Health Survey of 1995, between 1989 and 1995 there was a reduction in the number of sexual partners. There was also a six-month increase, to about 16 years, in the median age of girls' first sexual intercourse. However, IEC outcomes have been constrained by social and cultural obstacles to behaviour change; inadequate, or complete lack of research on the impact in the different population categories; and inappropriate messages in terms of content, medium and target group. For example, specific IEC messages should be developed for high-risk groups and vulnerable people, such as children and adolescent women.

**Voluntary HIV counselling and testing:** Voluntary counselling and testing (VCT) has proven critical in determining changes in behaviour, attitudes and intentions necessary to reduce or eliminate individual risk of exposure to HIV. VCT services were pioneered by an NGO, the AIDS Information Centre, in the early 1990s. As of 2002, over half a million people had accessed VCT services, available in 31 out of 56 districts with support from the United Nations Population Fund (UNFPA). The MoH STI/ACP programme estimates that the average cost of one VCT encounter is \$12, excluding the cost of buildings and counsellor time. These costs compare favourably with those reported for VCT in Kenya (\$27) and United Republic of Tanzania (\$29).

It is government policy for VCT to be universally available and accessible to all citizens. Informed consent and confidentiality is observed and HIV testing is not part of routine medical examinations without the knowledge of the client. VCT is now integrated into health services at district level and it is planned to extend testing services to health centres at subcounty level.

However, many still fear breach of confidentiality and are thus unwilling to be tested. Moreover, the programme has generally been constrained by the limited number of counsellors, the low quality of the testing facilities available at some sites (e.g. staff, laboratories and consumables), and high population mobility, which makes it difficult for certain groups, such as children and youth, to access VCT services.

In addition to voluntary testing, there is compulsory testing and quarantine of certain groups. The 1993 Operational Plan foresaw compulsory HIV testing of students going for long courses abroad because of the state investment in their education, but this requirement was dropped so that the only groups currently undergoing compulsory testing are the army, police and prison guards. This is due to the high costs of training recruits and the expectation that they should be able to work for at least 10 years after their training.

**Prevention of blood-borne HIV transmission:** In order to reduce the transmission of HIV and other diseases through contaminated blood, the MoH started the Uganda Blood Transfusion Services Project in 1987. Largely funded from the

outset by the European Union, the project was due to be 100 per cent funded by the government from 2004 onwards. More than two thirds of those given blood are children under 12, so safe blood transfusion is a key strategy in prevention of HIV in children. The service is considered to be the best in Africa, with 98 per cent of the blood being safe. Since 1997, the service has been a regional training centre for anglophone Africa.

Efforts have been made to sensitize blood donors, medical workers and the public about the dangers of excessive use of blood transfusion and using non-sterile needles or other skin piercing instruments, but there has been no specific training on HIV prevention for barbers, traditional birth attendants or healers. Also, although regional blood screening and transfusion services have been established, the inadequate dissemination of new techniques for detecting contaminated blood is still a big constraint.

**Uganda's participation in the development of a HIV vaccine:** Uganda has joined the rest of the world in the search for curative and preventive drugs for HIV. At the Bangkok XV International AIDS Conference in July 2004, President Museveni promised to provide the leadership necessary to ensure Uganda's participation in research efforts.

The Uganda Virus Research Institute/International AIDS Vaccine Initiative (UVRI/IAVI) HIV vaccine programme in Entebbe is one of the many sites where volunteers can participate in trials to find effective vaccines for use in Uganda and elsewhere in Africa. In 2005, the programme was conducting a DNA/MVA Phase I vaccine trial with 50 volunteers. Plans are underway to begin enrolling volunteers for other similar vaccine trials. The trials are all conducted according to protocols approved by the UVRI's Science and Ethics Committee and the Uganda National Council for Science and Technology. To ensure high ethical standards and protection of the volunteers, the trials are monitored by three different independent bodies: a Trial Steering Committee, a Data Monitoring and Ethics Committee and a clinical research organization.

To highlight HIV vaccine research activities and challenges, an HIV vaccine awareness day was held in May 2004. Under the theme '**Imagine a vaccine to prevent HIV/AIDS**', a number of activities were held, including a 6-km walk in Entebbe. Appreciation and support were expressed for both the trial volunteers and the scientists engaged in the research.

## **Care and treatment of HIV and related illnesses**

Despite the limited capacity of the government health system, there have been a number of achievements in partnership with the NGO/CBO sector. These include: promotion of improved health-care services through home-based care and

community outreach; training of 500 counsellors, allowing for at least two per hospital and up to four in those with an active PMTCT programme; training of district officers in infection-control techniques and of at least one service provider per facility in administration of drugs for opportunistic infections; development of nursing care guidelines and a counsellors' training guide; distribution of drugs for the treatment of opportunistic infections and home-care kits to government and NGO health units. The government has produced various guidelines for people living with HIV, spelling out the importance of good nutrition to alleviate common nutritional disorders in HIV infection, including protein-energy malnutrition, specific micronutrient deficiencies such as iron, vitamins A, B and E, selenium, albumen and zinc and clinical conditions affecting the gastrointestinal tract. The guidelines provide specific menus, with recipes and their respective nutrient values.

There are, nevertheless, shortcomings in the care and treatment of HIV. Some people, medical personnel not excepted, discriminate against those living with the virus. Moreover, infected or affected people are insufficiently involved in prevention and control themselves and many do not acknowledge their serostatus. Although there are now agreed protocols for treating various opportunistic diseases related to HIV, the current regimens used, even effective herbal medicines, are too expensive for a great many patients. The country still has inadequate policies on the use and monitoring of antiretroviral drugs and there are informal reports of blackmarket ARVs being used outside licenced practices.

### **Antiretroviral therapy**

Following successful implementation of the pilot UNAIDS/MoH HIV Drug Access programme in Uganda in 1999, a National Strategic Framework for the Expansion of HIV/AIDS Care and Support was developed, together with policies and guidelines on antiretroviral therapy (ART), PMTCT, VCT and the role of nutrition in AIDS.

Uganda is participating in the global '3 by 5' Initiative to deliver antiretroviral therapy to 3 million AIDS patients worldwide by the end of 2005, the target for Uganda being 60,000 patients. The major hindrance to expansion of ART had been prices, but following global advocacy to reduce costs for low- and middle-income countries, there has been increased access. As of April 2004, the cheapest triple combination pre-qualified by WHO cost \$244 per patient per year (Médecins Sans Frontières 2004). Over 80 per cent of clients paid for their treatment, but the government managed to leverage resources through a number of mechanisms and initiatives in an effort to provide free ART to the population. Funding programmes include: \$3 million from the World Bank (MAP Project) to treat 6,000 patients for one year; \$10.6 million from the Global Fund to Fight AIDS, Tuberculosis and Malaria for the period 2004–2006; and another \$36 million from the fund for 2005–2007. The US President's Emergency Plan for AIDS Relief (PEPFAR) was initiated

in 2004 and provides funds for treatment of 60,000 people over five years. This is being implemented through four organizations: Catholic Relief Services will treat 2,700 people in seven health facilities during the first year and then scale up over five years; The AIDS Support Organization (TASO) will treat 3,000 in the first year, 7,000 in the second year and 10,000 in the third year in TASO centres; a further 1,300 will be treated by the Mildmay Project; and another 200 by the Rakai Project. In addition, a number of private employers treat their employees and several government ministries such as Public Service and Finance have plans to provide ART to their staff.

The number of patients on ARVs increased from 55 in 1996 to about 53,000 by December 2004. This figure represented coverage of 52 per cent of the estimated 114,000 people 15–49 years of age who actually needed ART (WHO and UNAIDS 2005). The government also endeavours to provide affordable drugs for opportunistic infections, particularly anti-TB drugs, which are provided free to all those who need them.

### Prevention of mother-to-child transmission of HIV

Mother-to-child transmission of HIV (MTCT) is the second most common mode of HIV transmission in Uganda. Approximately 1.2 million women are expected to be pregnant each year. With the current HIV prevalence of 6.2 per cent, this translates to about 74,000 pregnant women testing HIV-positive annually. Given a total vertical transmission rate of 30 per cent, an estimated 22,000 children will be born with HIV infection if nothing is done. This poses a significant burden on the children, their families and the health-care system.

The PMTCT programme was initiated in Uganda on a pilot basis in 2000, with strong support from UNICEF. By November 2004, Uganda had achieved national coverage of the programme, with a total of 235 PMTCT sites, each of the country's 56 districts having at least one functional site, and several having more than one.

**Table 9. National PMTCT scale-up plan (2000–2005) and achieved coverage**

Year	Planned sites	Cumulative number of districts with PMTCT (planned)	Actual districts with at least one site (cumulative)	Coverage by district
2000	3 (modelling phase)	3	3	
2001	8	11	4	8%
2002	17	28	22	40%
2003	10	38	34	61%
2004	18	56	56	100%

This rapid expansion has been achieved in partnership with other development partners. As of end-2004, the cumulative number of women and children benefitting from the programme was as follows: 512,090 pregnant women had accessed antenatal care services, including HIV testing, at PMTCT sites; 394,642 (80 per cent) of these women were counselled for HIV; 240,944 accepted HIV testing and 25,090 (10 per cent) tested HIV positive. A total of 13,866 HIV-positive pregnant women received prophylactic ARVs, together with 8,719 babies. Data on the number of children treated with ARVs is incomplete, as not all women who receive nevirapine during antenatal visits return to deliver at the health facility and some may have miscarriages. Below is a graph showing the overall performance of the PMTCT programme from January 2000 to end-2004.

**Figure 6. Performance of PMTCT programme 2000–2004**

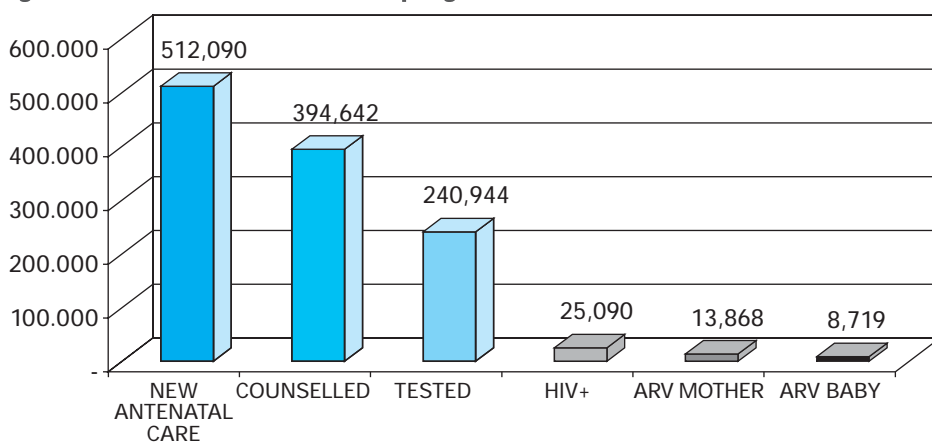


Table 10 shows ARV drug costs for PMTCT based on Modified Thai, Petra Arm A and Nevirapine.

**Table 10. Cost of antiretrovirals for PMTCT of HIV**

Number of mother–baby pairs	Cost per regimen		
	Modified Thai1 \$	PETRA Arm A 2 \$	Nevirapine \$
One mother–baby pair	125.0	90.0	1.0
109,200 mother–baby pairs	13,650,000	9,828,000	109,200
54,600 mother–baby pairs	6,825,000	4,914,000	54,600

Source: MoH Uganda, PMTCT Scale-Up Plan 2001–2005.

There are still a number of cultural and systemic constraints to preventing mother-to-child transmission of HIV. Moreover, breastfeeding is the norm for infants in Uganda and there are few alternatives, particularly in rural areas, so where large



family sizes are traditionally associated with security, prevention of MTCT may encourage HIV-positive couples to have children. The limitations of Uganda's health system, which covers 85 hospitals and 1,800 health centres (dispensaries, subdispensaries and maternity centres), mean that there is inadequate medical supervision for mothers who give birth at home, and there are few staff available to offer counselling, testing and follow-up of clients after delivery. There are no counselling rooms in hospitals and insufficient laboratory facilities to monitor women who are on antiretroviral therapy.

### **Interventions in the education sector**

The education and sports sector is a unique tool for spreading HIV and AIDS information and awareness. As an already organized infrastructure, it is cost-effective and can reach a large audience of teachers/instructors and administrative staff, pupils and their parents, as well as sportsmen and women outside the education mainstream. Since 1994, there have been initiatives to institutionalize preventive education in the sector by integrating HIV issues into the curricula at different levels of formal education. These initiatives include:

- **The Early Life Skills Initiative**, which trains young people in skills such as interpersonal relationships; self awareness and self-esteem; problem-solving; effective communication; decision-making; negotiation skills; resisting peer pressure; critical thinking; and formation of friendships. The initiative was developed to bridge the gap between high levels of knowledge and awareness about HIV and AIDS and lagging behaviour change.
- **The UNICEF-supported Sara Communication Initiative**, which aims to develop girls' life skills.
- **IEC in support of reproductive health** is intended to impart knowledge and skills about all aspects of reproductive health, not only STIs and HIV transmission.
- **Sensitization seminars** on the HIV epidemic for the 500-strong Ministry of Education and Sports workforce. However, lack of policy, plan and funding inhibited effective sensitization and advocacy relevant to the epidemic.

Interventions directly related to children orphaned by AIDS have been ad hoc and largely limited to situation analysis. The government does not have any special provision for such children in the UPE programme. Although limited by lack of funds, NGOs run a number of practical projects, providing medical care, social welfare benefits such as payment of school fees and supply of scholastic materials, and necessities for the home, including soap and food.

### **The District Response Initiative**

The goal of the District Response Initiative is to create HIV-competent communities where all elements of society are enabled to appreciate the reality of the epidemic,

take action to prevent its spread, improve the quality of lives of infected people and support affected people and their families.

The initiative was developed through a consultative process involving government ministries, AIDS service organizations and development partners, both at district and national level, with technical assistance from UNAIDS. The communities are able to mobilize local and international resources and mainstream HIV control activities across all sectors. However, the initiative is not child-specific.

### **Uganda's National Programme of Action for Children**

Since 1992, there has been increased attention towards the development of policies that address children's problems, particularly those related to the HIV epidemic. The government has therefore instituted some specific legal statutes and policies. The Convention on the Rights of the Child set the stage for the development of the Uganda National Programme of Action for Children. The government then formulated and ratified the Children's Statute in 1996. This statute addresses the rights of children as stipulated by the child rights convention and the Organization of African Unity (OAU) charter on the rights and welfare of children (National Council for Children and UNICEF 1999). It provides a comprehensive legal and institutional framework for the protection of Ugandan children and stipulates that local councils and communities have a duty to protect children whose parents have died. However, there are still several gaps that prevent the statute adequately addressing children's problems: inheritance laws are still weak and there are no specific legal protections for orphaned children.

The National Council for Children (NCC) was established under the statute in 1996 mainly "to provide a structure and mechanism to ensure proper coordination, monitoring and evaluation of all policies and programmes relating to the survival, protection and development of the child and other connected matters" (NCC 1999). At the district and community levels, there are probation officers, Secretaries for Children's Affairs and Public Welfare Assistants to promote and supervise implementation. There is also a Family Protection Unit in the Uganda police to help resolve family issues, including those of vulnerable children. Unfortunately, however, the existence of these laws and staff does not ensure enforcement. There are still weaknesses that render the council ineffective in addressing the problems of children.

The government has developed a National Orphans Policy and Strategy in order to have a comprehensive approach for orphans and other vulnerable children (UNAIDS 2004). Although the crisis caused by the numbers of children orphaned by AIDS was recognized early on, from 1998 to 2000 only an estimated 5 per cent of the children received any government help (Deiningert et al. 2003).

## The stakeholders

### The Government

The Government of Uganda is at the forefront of controlling the spread of HIV. Over the five-year period 2000–2005, the national HIV response was estimated to have cost \$181,466,030, or 3 per cent of total government expenditure. Table 11 shows that priority is given to prevention, with it totalling 46.1 per cent of the estimated total cost. About a third is devoted to mitigation of the health and socio-economic effects of HIV, and 21 per cent to strengthening national capacity to respond to the epidemic. It should be noted that these figures include all categories of society and are not specific to children.

**Table 11. Breakdown of cost estimate for the HIV plan by goal/major activity (in \$)**

Item	5-year cost estimate	%
Goal 1: Reduction of HIV infection by 25% by 2005/6	83,707,680	46.1
Goal 2: Mitigation of effects of HIV	59,672,693	32.9
Goal 3: Strengthening national capacity for response	38,085,657	21.0
Grand Total	181,466,030	100.0

Source: The National Strategic Framework for HIV/AIDS Activities in Uganda 2000/1–2005/6, March 2000.

### The social welfare sector

The Ministry of Gender, Labour and Social Development is responsible for staff sensitization and awareness on HIV and AIDS, counselling services and condom distribution. One of its most successful activities is the Programme for Enhancing Adolescent Reproductive Life (PEARL), which emphasizes reproductive health in general, and HIV and AIDS in particular, among adolescents. PEARL has recruited officers in 143 subcounties from the 22 districts where it operates, and is engaged in disseminating relevant information and capacity-building through training at all levels. The ministry also has plans to resettle street children in a rehabilitation centre and provide educational facilities.

### The education sector

The infrastructure of the education sector constitutes a unique tool for spreading HIV information and awareness. It is cost-effective and can reach a large audience of teachers/instructors and administrative staff, pupils and their parents, as well as sportsmen and women outside the education mainstream.

In April 2001, the sector produced an HIV strategic plan 2000/1–2005/6, which focuses on key intervention areas, such as developing policy guidelines that promote

prevention and mitigation of the epidemic, HIV education, advocacy and mobilization, including establishment of VCT services in institutions, and welfare programmes for HIV-positive staff and children orphaned by AIDS. The plan also foresees setting up education bursaries/scholarships and material support for school-children, particularly those orphaned by AIDS. The orphan scheme will initiate income-generating activities such as poultry, horticulture and arts and craft.

### **The health sector**

The MoH STI/ACP programme handles sexually transmitted infections (STIs) and HIV control and prevention. This programme is run by a workforce of 10 full-time staff, consisting of epidemiologists, public health physicians and health educators. It carries out HIV-control activities and has seven broad areas of operation: infection control; information, education and communication; care and support; laboratory and blood transfusion services; condom promotion; epidemiological surveillance; and STI control. The establishment of the World Bank-funded \$73-million STI Project under MoH in 1994 brought a necessary capital injection into health sector HIV control.

Control of HIV infection is handled through infection control committees in hospitals and focal persons in health centres. MoH has 15 sentinel sites in hospitals for establishing prevalence in the country. In addition, it has health educators in all districts to spearhead IEC activities. There are plans to ensure that each referral facility has a health educator. Through the STI/HIV control programme, the Ministry offers refresher courses to these committees and key persons. There is an ongoing programme of training health workers in counselling and use of ART. In conjunction with the MildMay Centre, patients are trained in management of terminal cases of AIDS. The training of health workers to manage opportunistic infections has been incorporated into an ongoing pre- and in-service training programme as one of the key health challenges in the country.

Although there has been massive recruitment of doctors, nurses and paramedics to address gaps in service delivery, there are still staff shortages in all health facilities.

The challenges of HIV prevention threaten to absorb the public health budget, while the increasing burden of HIV-related diseases in health facilities puts similar strain on curative services. Annual per capita health expenditure totals from \$7 to \$12, with only \$4 attributed to government and donor spending, the balance coming from individuals.

Curative services, which cover care of HIV-related diseases, account for over 60 per cent of all health expenditure. Less than 10 per cent of the total health budget is allocated to HIV programmes.

In order to increase access to health care, in March 2001, MoH abolished user fees (which had been in place for the past decade) in all government-owned units other than the private wings. The government has established secondary-level referral facilities (with an operating theatre, an anaesthetist, a doctor and a public health nurse) in all counties to cover an average population of 100,000 people. This has led to construction of 134 referral health centres, which are largely mini-hospitals. Most of the recruited staff have been posted to rural health facilities and NGO facilities located in underserved rural areas. The government provided grants, covering up to 50 per cent of recurrent expenses, to NGO hospitals and health centres. The sector plan provides for construction of a health centre for every 5,000 people in order to increase geographical access.

### **NGOs, CBOs and international agencies**

Both local and international NGOs have played a major role in assisting and protecting children, particularly those orphaned by AIDS, by providing food, school fees, shelter, clothing, basic training, income-generating schemes and counselling. In October 1996, CBOs, FBOs and NGOs with an AIDS component in their activities/programmes formed a nationwide network called Uganda Network of AIDS Service Organisations (UNASO) to coordinate HIV activities, promote common standards for implementation, monitoring and evaluation and strengthen delivery effectiveness. UNASO is affiliated to the African Council of AIDS Service Organizations (AfriCASO), and now has a membership of over 2,000 relevant organizations.

Through an operational secretariat headed by a coordinator and six other staff, UNASO has set up district networks of AIDS service organizations and supported development of the organizational skills capacity of 65 NGOs/CBOs/FBOs. But there are limitations to UNASO's involvement in HIV-control activities, as capacity has to be built in UNASO itself, as well as the local NGOs, FBOs and CBOs. Moreover, all the local NGOs largely depend on external donor support or on government loans and grants, which raises questions of sustainability.

Among the major players is the **Uganda Community-Based Association for Child Welfare (UCOBAC)**, which was established as a network of organizations providing support to vulnerable children. This institution, with support from UNICEF and other international NGOs, has developed a 'grants bank' that has helped donors, CBOs and NGOs work together. UCOBAC provides a monitoring and support function for such programmes and it trains CBOs and NGOs.

The most high profile organization in the field is **UWESO**, mentioned earlier. UWESO works through sustainable interventions and programmes that build local capacity and provide sustainable mechanisms for the support of children orphaned by war or AIDS.

UWESO programmes support vocational training, HIV counselling, income-generating activities, day-care centres and school fee sponsorship. It has over 5,000 active members who volunteer to identify needy orphans, link them with foster families, serve as foster parents, monitor school fee payments, and engage in income- and food-generating activities. By the end of 2001, UWESO was reaching over 120,000 children and was only constrained by financial limitations from extending coverage to all children orphaned by AIDS or war. To qualify for support, the child should have lost one or both parents, be under 18 and live with a relative. This guardian relative then becomes a member of UWESO.

Apart from UWESO, there are estimated to be over 150 national and international organizations providing support and care for children and orphans. However, these organizations need better coordination, integration, financial support and monitoring in order to reduce duplication.

**AIDS Information Centre:** The AIDS Information Centre (AIC) contributes to the national effort to prevent further spread of HIV infection by providing counselling and advice for those already infected and affected by HIV and promoting the adoption of healthy lifestyles. It operates in four urban areas – Kampala, Jinja, Mbale and Mbarara – and is in the process of decentralizing its HIV counselling and testing services to enable it to reach 16 districts. The services offered include:

- **Voluntary and anonymous HIV counselling and testing.** This service is offered Monday through Saturday at a minimal fee. Counselling is a prerequisite for testing, and there is strict confidentiality, with no written record of the results given to clients.
- **Detection and management of other STIs.** All clients who consent to take the HIV test are also screened for syphilis and treated where necessary. Clients may be tested for syphilis only if they wish.
- **Condom education and distribution.**
- **Information and counselling on family planning.** All clients who come to AIC receive information, education and counselling. Counsellors and reproductive health volunteers help clients make informed decisions about which family planning methods to use. AIC provides clients with pills, condoms, spermicides, injections and referrals for other methods. Pregnancy tests are also done at no cost.
- **TB education and referrals.** Information and counselling on TB is given to all clients who seek VCT services.
- **Psychosocial and medical services** are offered through the Post Test Club.

**TASO:** TASO was the first indigenous community-based organization, founded in 1987 by a group of 16 committed volunteers, most of whom were directly affected

by HIV and many of whom have since died. TASO has grown into one of the biggest organized national responses to the HIV epidemic, with eight branches countrywide. It works closely with AIC and other related institutions. TASO receives funding from MoH, international agencies such as the United Kingdom Department for International Development (DFID), and the European Union.

**The Straight Talk Foundation:** The Straight Talk Foundation has influenced sexual behaviour in many young Ugandans. It publishes two monthly newspapers, *Straight Talk* and *Young Talk*, which reach over 1 million young people in primary and secondary schools. The Foundation's aims are to increase understanding of adolescents and their sexual and reproductive health, and to promote safer sex, life skills and the rights of children and adolescents.

The *Straight Talk* newsletter was launched in 1993 to give in-school teenagers and young people aged 15 to 24 reliable information about sexual and reproductive health. The newsletter started with a print-run of 30,000 and immediately generated such an enthusiastic response from young people and teachers that by October 1999, 155,000 copies were being printed every month. *Straight Talk* advocates abstinence and condom use as protective strategies for its readers. It is supplied to all 1,400 secondary schools in Uganda (30 copies per school) and to over 400 tertiary institutions. Approximately 400,000 young people read the publication regularly. *Young Talk*, which has a monthly print-run of 270,000, was launched in February 1998. Targeting young adolescents aged 10 to 14 attending primary school, it advocates sexual abstinence, but provides information about condoms whenever requested by readers. The newsletter is sent to teacher training colleges and to all the country's 12,000 primary schools, with each school getting 15 copies.

## Traditional healers

In an effort to diversify efforts against HIV, MoH encouraged traditional healers to work with the modern-trained health providers through the AIDS Control Project. A 1998 evaluation showed that herbal treatments were in some instances more effective for herpes zoster and chronic diarrhoea among patients with HIV-related illness than available modern medicines. In order to improve traditional providers' skills, MoH set up a training programme covering patient care, counselling, record management, hygiene, prevention of HIV infection, and identification and referral of cases. The healers are required to attend monthly meetings and are monitored by the NGO Traditional and Modern Health Practitioners Together Against AIDS (THETA 1999).

## The role of the extended family

The African tradition of the extended family providing a safety net for members in time of need is declining fast because of poverty and immediate family demands. A

study by the Medical Research Council (UK), based on data collected by counselors, on the care given to 30 patients diagnosed with AIDS by their families (17 women, 13 men), showed that 27 of the 30 cases received limited care due to lack of food, lack of money for medication and other family responsibilities. For the 17 clients who died during the study period, records of 7 cases show that other relatives were asked to help with care, but refused on grounds of poverty or other commitments. In only one case did the extended family provide assistance for the funeral.

### **The business sector**

In addition to international business firms involved in HIV treatment, there are two local business organizations spearheading the role of the business sector. The Uganda Business Coalition on HIV/AIDS (UBC-HIV/AIDS), which includes the Private Sector Foundation, Small Scale Industry Organization, Uganda Chamber of Commerce and Industry and Federation of Uganda Employers, aims to reduce the rate of new HIV infections in business workplaces and mitigate the socioeconomic impact of HIV in the private sector. The organization has linkages with international organizations such as the Global Business Council on HIV/AIDS and pharmaceutical companies. A sister organization is the Uganda Business Council on HIV/AIDS, focused on work-related HIV interventions. Both organizations are actively involved in negotiations with the Global Fund to Fight AIDS, Tuberculosis and Malaria.

### **Lessons learned**

The prevention, treatment and mitigation of HIV and its effects on children can succeed if there is political commitment from the highest to the lowest levels of government. In Uganda, most of the achievements made so far may be attributed to government policies of openness, advocacy and resource mobilization. HIV is given the priority it deserves and accorded the same status as other priority development areas such as agricultural research and extension, maintenance of roads, basic education, rural water supply and primary health care.

The effects of HIV on children are long lasting and profound. Since children are the future of Uganda, more efforts are needed to ensure that as many children as possible who are born to HIV-positive mothers are not infected.

There is need to provide further educational opportunities to vulnerable children at primary, secondary, vocational and tertiary levels of education so as to enable them to attain some degree of economic independence.

The involvement of local and international NGOs, CBOs and FBOs in all areas of service-delivery and policymaking has brought all key stakeholders on board and achieved wide coverage. Communities and individual families have also been



involved in the control, treatment and mitigation of the consequences of HIV. Although these are very good lessons for other countries, Uganda still has large gaps that need to be addressed if the current momentum is to be kept on track.

## **Recommendations**

In order to achieve further reductions in HIV infection, interventions and responses to HIV with a child-specific component should be included on the national agenda – with an adequate budget commitment. The current move to strengthen capacity and coordination for protection of children at national and district level should be enhanced. Strengthening of the district response through strategies such as the Direct Response Initiative and the Community HIV/AIDS Initiative (CHAI) should be encouraged. Also, the Children’s Statute should be implemented and the NCC strengthened.

Behavioural change remains the mainstay of HIV control and therefore innovative strategies need to be put in place to influence such changes. A holistic approach should be encouraged if long-term behavioural change is to be realized in all groups of the population. As there is no AIDS cure yet, much more emphasis should be put on a broad spectrum of prevention programmes, especially those targeting high-risk groups. These include a 100 per cent condom distribution policy to all vulnerable groups, and the involvement of people living with HIV, students’ organizations and children’s groups, such as scouts and guides.

Child-specific data and information on seroprevalence for specific groups of the population should be collected so that a management information system can be developed. This will help in designing specific interventions, not only for children, but also for all vulnerable groups. The information for the specific groups should also be linked to knowledge, attitudes, beliefs and practices regarding HIV, so as to establish the factors that influence prevalence trends.

Uganda lacks specific legislation on HIV. This leaves the population at risk, particularly vulnerable groups such as children and women. It should be noted that the existing laws focusing on children have not been effectively implemented and some need to be amended.

Despite the contributions by the government, NGOs and donor community towards the control and treatment of AIDS, the country still faces limitations in resources to combat the pandemic. Efforts must be intensified to mobilize resources from both within and outside the country. This should also include efforts to foster regional groups, such as the Great Lakes Initiative, to increase the availability of interventions, including access to ART and condoms, through economies of scale. By encouraging regional groupings, there can be sharing of experience among the members and scaling-up of successful practices.

There has to date been limited use of economic modelling when designing programmes to respond to AIDS. UAC, in collaboration with UNAIDS, line ministries and agencies, could consider convening a working party composed of multi-disciplinary professionals, with a critical mass of health economists, in order to address these policy gaps. There is a need to carry out further research on the cost-effectiveness of intervention programmes such as large-scale use of ART. The country also urgently needs to develop a policy on how to administer and use ART, for the guidance of health workers and the public at large.

The Government of Uganda, NGOs, CBOs and the donor community should put more benefits in place for orphans, including those orphaned by AIDS, as a way of addressing such problems as street children. The response to AIDS will continue to require strong partnership and commitment on the part of the government, the business sector, NGOs, the donors and civil society, including the general population. Only a joint effort in the response to AIDS will help reduce the impact of the epidemic on children and the general population.

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## Notes

- 1 Data on attrition and mortality for years other than 1995–1998 were not available.
- 2 Teacher attrition includes leaving the service through resignation, leaving without notice, death or retirement. Transfers, secondment or leaving for training are not regarded as attrition.
- 3 Based on a WHO estimate that HIV/AIDS accounted for 20.6% of the mortality in sub-Saharan Africa in 1999.